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Quality of End-of-Life Care for Older Adults with Dementia during the COVID-19 Pandemic



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A B S T R A C T

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Objectives: End-of-life (EOL) care during the coronavirus disease 2019 (COVID-19) pandemic has been a concern under the overwhelming pressure of health care service systems. People with dementia often receive suboptimal EOL care; thus, they may be at particular risk of poor care quality during the COVID-19 pandemic. This study investigated the interaction between dementia and pandemic on the proxies' overall ratings and ratings for 13 indicators.

Design: A longitudinal study.

Setting and Participants: Data were collected from 1050 proxies for deceased participants in the National Health and Aging Trends Study, a nationally representative sample of community-dwelling Medicare beneficiaries aged ≥ 65 years. Participants were included if they had died between 2018 and 2021.

Methods: Participants were categorized into 4 groups depending on the period of death (before vs during the COVID-19 pandemic) and having no vs probable dementia, as defined by a previously validated algorithm. The quality of EOL care was assessed through postmortem interviews with bereaved caregivers. Multivariable binomial logistic regression analyses were performed to examine the main effects of dementia and pandemic period, and the interaction between dementia and pandemic on ratings of quality indicators.

Results: A total of 423 participants had probable dementia at the baseline. People with dementia who died were less likely to talk about religion in the last month of life than those without dementia. Decedents during the pandemic were more likely to have an overall rating of care as being not excellent than those before the onset of the pandemic. However, the interaction between dementia and pandemic was not significant in the 13 indicators and the overall rating of EOL care quality.

Conclusion and Implications: Most EOL care indicators preserved the level of quality, regardless of dementia and the COVID-19 pandemic. Disparities in spiritual care may exist across people with and without dementia.

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Dementia, caused by Alzheimer's disease and other related disorders, is a chronic condition that affects memory, thinking, and social abilities. The median duration of survival after a diagnosis of

dementia was 5 years, which was considerably shorter than that for older adults without dementia.¹ During this period, people with dementia may experience progressive cognitive decline and loss of capacity for meaningful communication.² Hence dementia is a life-limiting condition that requires palliative care.³ The global number of people with dementia is estimated to increase from 57.4 in 2015 to 152.8 million cases in 2050.⁴ Such a rise in dementia represents an escalating global burden of palliative care needs.⁵ Dementia was the seventh leading cause of death in the United States in 2020 and 2021.⁶ People with dementia often receive suboptimal end-of-life (EOL) care,⁷ including poor communication and inattention to personal care needs,⁸ and poor pain management.^{9,10} The

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emergence of the novel coronavirus disease in 2019 (COVID-19) has challenged end-of-life care for people with dementia. The United States experienced substantial excess mortality related to the COVID-19 pandemic in 2020 and 2021.^{11,12} Therefore, the health care service system has seen an increase in the number of seriously ill people cared for. Besides the sustained and overwhelming pressure,¹³ the restrictions to minimize infection transmission have limited in-person communication among patients, families, and health care teams.¹⁴ As people with dementia are at particular risk for COVID-19 and mortality,^{15,16} these restrictions may be most strictly adopted for them, resulting in reduced communication and poor care quality at the end of life. However, there is little evidence of the quality of EOL care among people with dementia during the COVID-19 pandemic.

This study aimed to investigate the interaction between dementia and pandemic on the proxies' overall ratings and ratings for 13 indicators. We hypothesized that the negative impact of the pandemic on quality of EOL care was greater among older adults with dementia than those without dementia.

Methods

Design and Approvals

We used a retrospective longitudinal study design. National Health and Aging Trends Study (NHATS) is led by the Johns Hopkins University Bloomberg School of Public Health and the University of Michigan's Institute for Social Research, with data collection by Westat. The National Institute on Aging provides support for NHATS (Produced and distributed by www.nhats.org with funding from the National Institute on Aging [grant number U01AG32947]). This study was approved by the Johns Hopkins Medicine Institutional Review Board.

Participants

The participants were drawn from the NHATS, an ongoing nationally representative population-based study of Medicare beneficiaries aged 65 years or older in the United States.¹⁷

NHATS enrolled 8245 participants at the baseline in 2011. The participants or proxy respondents were followed by annual in-person surveys. In 2015, a new sample was introduced to restore the sample to the original size by age and race groups. Details of the design and protocol for the NHATS are available elsewhere.¹⁸

Our sample was extracted both from the initial and refreshment samples and included 1050 NHATS participants whose deaths were identified between 2019 and 2021, including decedents both before and during the COVID-19 pandemic. The participants were categorized into 4 groups based on the period of death and dementia status (Figure 1).

Measurements

Dementia status was identified in the NHATS round before death (ie, dementia status assessed in the 2018 round was used for classifying 2019 deaths), based on the validated algorithm for use in surveys¹⁹: report of physician diagnosis, proxy responses to the AD8 dementia screening interview,²⁰ and cognitive testing.

The period during the COVID-19 pandemic was defined as starting from April 2020, based on the epidemic and excess deaths in the United States.²¹

Data on EOL care quality were obtained from the last-month-of-life interviews, which focused on understanding the quality of EOL care for people who died between rounds. Proxies were asked to rate the overall rating and ratings of the 13 indicators, which have been validated from a National Quality Forum measure that assesses the following domains: pain and symptom management, communication

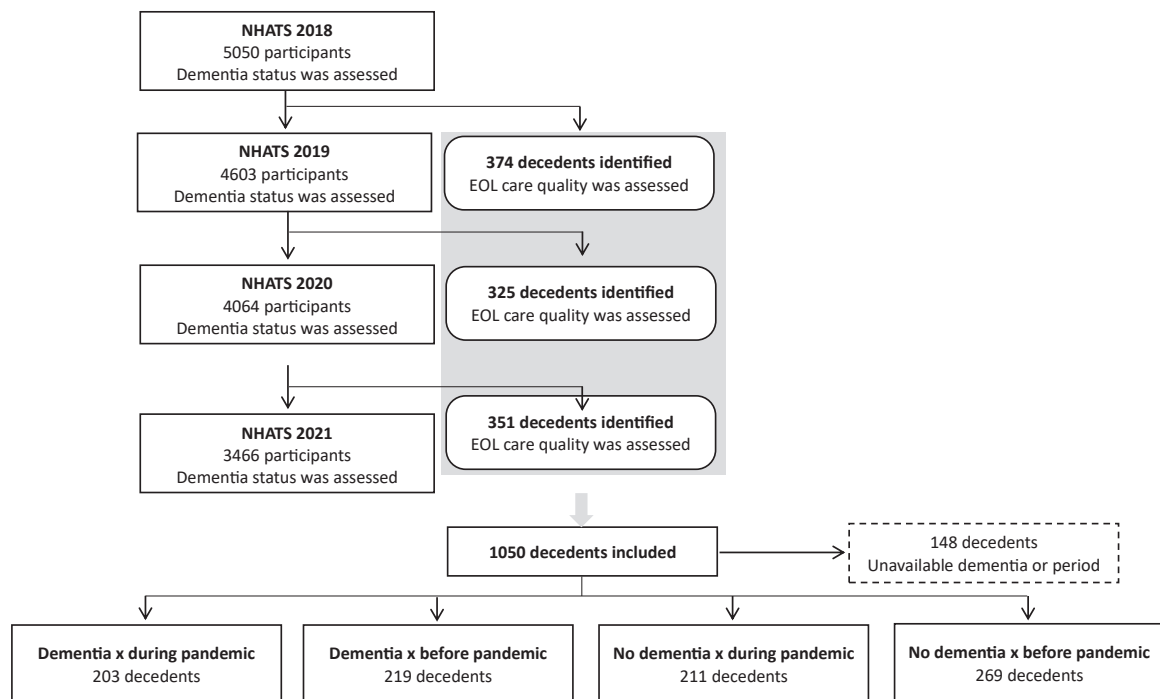


Fig. 1. Flow chart of the study. Participants were recruited from the National Health and Aging Trends Study (NHATS), an ongoing nationally representative population-based study of Medicare beneficiaries aged ≥ 65 years in the United States. Dementia status was identified in the NHATS round before death based on a validated algorithm for use in surveys. Data on end-of-life (EOL) care quality were obtained from interviews conducted in the last month of life.

and decision making, emotional support, and an overall quality rating.²² To evaluate the pain and symptom management domain, proxies were asked whether the individual who died experienced a given symptom in the last month of life. If so, they were asked whether the individual received the right amount of help to address that symptom. Unmet needs for pain and symptom management were defined as the individual not receiving the right amount of help to address a given symptom. To build off prior literature,^{8,23,24} we dichotomized variables using Likert scales to compare the most positive rating with any less positive rating for adjusted analyses. For each indicator, higher proportion mean lower EOL care quality.

Covariates in this study were defined based on the literature,²⁵⁻²⁷ and included the participants' place of residence during the last month of life, whether hospice care was engaged, decedent's age at death, race or ethnicity (Caucasian, African American, Hispanic, and other), sex (male/female), and proxy's sex and relationship to the decedent: child, other family member, and nonrelative (staff member in the residential care settings or a care provider). Proxies were asked where the decedents lived in the last month of life and whether the decedents were enrolled in hospice care.

Statistical Analysis

The proportion and 95% CIs of the quality indicators were calculated across the 4 groups.

Because the use of hospice care has been demonstrated to improve EOL care quality in people with dementia,²⁶ the proportion of hospice care engagement was compared across the 4 groups. Unadjusted odds ratios (ORs) and 95% CIs were calculated using a binomial logistic regression model.

Multivariable binomial logistic regression analyses were conducted to test for differences in care quality according to dementia and the pandemic period. The first model used each outcome indicator as the dependent variable, and dementia status and period as the independent variables. All the covariates were included as independent variables. The second model added the interaction between dementia and pandemic as the independent variable to the first model.

In these analyses, the full information maximum likelihood was used to handle missing data.²⁸ All analyses were performed using Mplus for Windows, version 8.8 (Muthén & Muthén). Statistical significance was set at $P < .05$.

Results

The characteristics and quality rating of the participants are listed in [Table 1](#). There were 423 participants (46.7%) who had probable dementia in the previous round and 468 participants (44.9%) who died during the pandemic. The period of death before the onset of the pandemic ranged from June 2018 to March 2020 and from April 2020 to November 2021 during the pandemic. Hospice care engagement was reported by 438 participants. The rate of poor care quality ranged between 8.7% and 78.1% across indicators ([Table 1](#)).

The proportion of hospice care engagement was higher in decedents with dementia during the pandemic than in those without the condition before (unadjusted OR = 0.584, 95% CI = 0.385–0.885; $P = .011$) and during (unadjusted OR = 0.484, 95% CI = 0.309–0.758; $P = .002$) the pandemic.

The proportion and 95% CIs of EOL care quality indicators stratified by dementia status and period are shown in [Supplementary Table 1](#). In general, 74% to 81% of the proxies reported that decedents

Table 1
Characteristics and End-of-life Care Quality Indicators of Decedents (N = 1050)

	No. of Responses	n (%)
Age at death, y, mean (SD)	1047	87.2 (7.5)
Sex, male	1050	419 (39.9)
Race/ethnicity	1030	
Caucasian		723 (70.2)
African American		227 (22.0)
Hispanic		58 (5.6)
Other		22 (2.1)
Proxy relationship to the decedent	1050	
Child		513 (48.9)
Other family member		510 (48.6)
Nonrelative		27 (2.6)
Proxy sex, male	1046	254 (24.3)
Place of residence	1050	
Private home		630 (60.0)
Residential care		420 (40.0)
Hospice care engagement within the last month of life	815	438 (53.7)
Probable dementia assessed in previous year	905	423 (46.7)
Period of death	1043	
Before the onset of COVID-19 pandemic (June 2018 to March 2020)		575 (55.1)
During the pandemic (April 2020 to November 2021)		468 (44.9)
Quality indicators (higher proportion means lower care quality)		
Experienced pain	950	742 (78.1)
Unmet need for pain management	921	139 (15.1)
Experienced breathing problem	968	551 (56.9)
Unmet need for breath	949	109 (11.5)
Experienced anxiety/sadness	931	554 (59.5)
Unmet need for anxiety/sadness	891	206 (23.1)
Decision made without enough input from decedent or family	997	87 (8.7)
Decision made that decedent would not have wanted	995	99 (9.9)
Family was not always kept informed	1022	193 (18.9)
Not always treated with respect	1013	119 (11.7)
Personal care needs not always met	1010	163 (16.1)
Not always clear with doctor in charge	620	128 (20.6)
Did not talk about religion	815	392 (48.1)
Overall rating of care was not excellent	1017	554 (54.5)

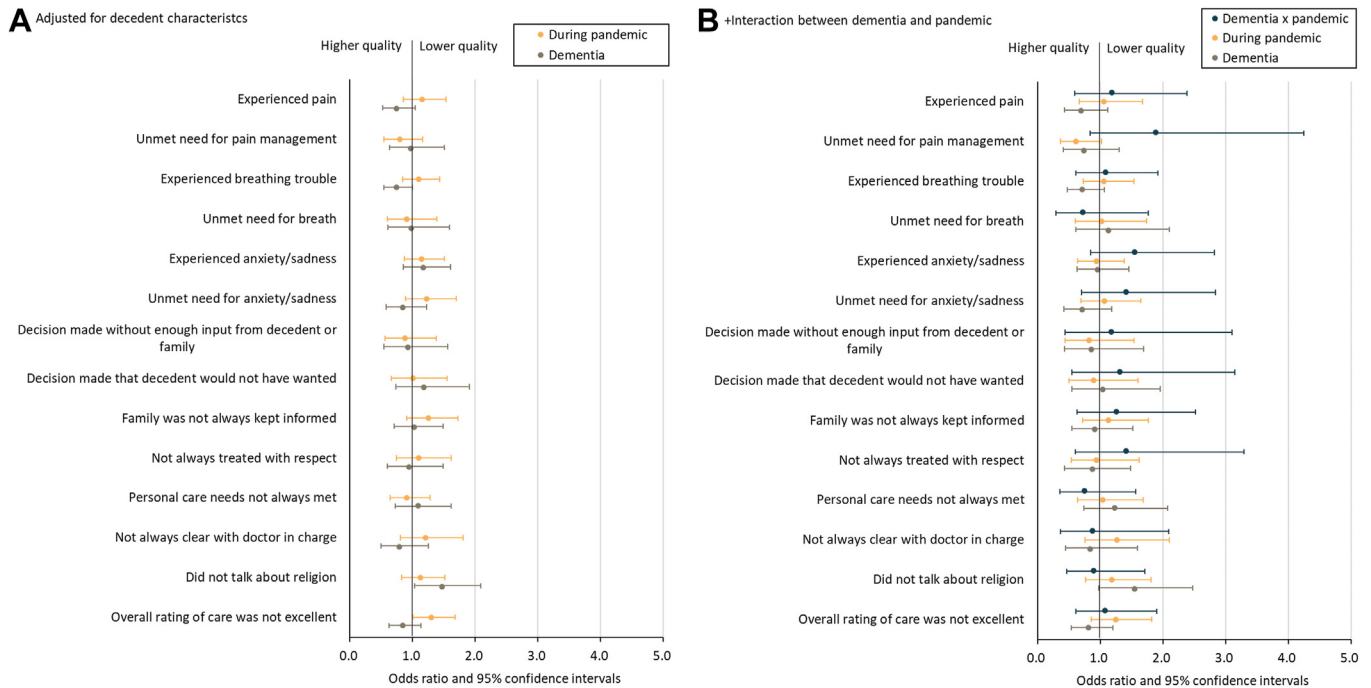


Fig. 2. Adjusted OR and 95% CIs of end-of-life care quality indicators by dementia, pandemic, and interaction between dementia and pandemic. (A) Adjusted ORs and 95% CIs for each indicator were estimated by the main effects of dementia status (probable vs no dementia) and period (before vs during the COVID-19 pandemic). (B) The interaction between dementia and pandemic was added to the first model (panel A). The full information maximum likelihood method was used ($N = 1050$). The binomial logistic regression model included age at death, sex, race or ethnicity, proxy relationship to the decedent, proxy sex, place of residence, and use of hospice care within the last month of life as covariates. Dot indicates the OR of the indicator, and line indicates the range of the 95% CI. Blue bars and lines refer to the interaction between dementia and during pandemic; orange, the main effect of pandemic; and gray, the main effect of dementia.

experienced pain; 54%–63% experienced breathing trouble, 58%–67% experienced anxiety/sadness, and 47%–52% did not talk about religion. Between 51% and 61% of proxies reported that the overall rating of care was not excellent (Supplementary Table 1).

The adjusted OR and 95% CIs of the quality indicators are presented in Figure 2. In the first model, persons with dementia who died were more likely to not talk about religion than those without dementia (adjusted OR = 1.470, 95% CI = 1.037–2.084). Decedents during the COVID-19 pandemic were more likely to have an overall rating of care as being not excellent than those before the onset of the pandemic (adjusted OR = 1.298, 95% CI = 1.002–1.680) (Supplementary Table 2). However, the interaction between dementia and pandemic was not significant in the overall rating and 13 indicators (Supplementary Table 3).

Discussion

The 4 groups of decedents by dementia status and period demonstrated similar levels of EOL care quality in the overall rating and 13 indicators. Dementia and pandemic were independently associated with poor EOL care quality. Individuals with dementia were more likely to have unmet religious needs than those without dementia. Decedents during the pandemic were more likely to have an overall rating of care as being not excellent than those before the onset of the pandemic. However, there was no interaction effect between dementia and the COVID-19 pandemic for any quality indicator.

Regardless of the dementia status and pandemic, the quality of EOL care was generally preserved for older adults in the United States. Hospice care engagement may have contributed to the absence of differences in EOL care quality according to dementia status or pandemic. The use of hospice care was suggested to improve EOL care quality for older adults with dementia,²⁷ and persons with dementia

in this study were more likely to be engaged in hospice care within the last month of life. However, the overall quality rating declined during the pandemic, suggesting that pandemic-related restrictions had an equal negative impact on people with and without dementia. Furthermore, poor care quality among people with dementia was observed in the rate of talking about religion within the last month of life. This result implies that people with dementia may be at a higher risk of unmet spiritual needs at the end of life. Although spiritual care for persons with dementia is recognized as being intended to help them express their faith and religious beliefs,²⁹ it receives less attention than advance care planning and psychological aspects of care in recommendations for palliative care for people with dementia.³⁰ Our findings highlight the existing disparities in spiritual care between persons with and without dementia.

Strengths and Limitations

The strength of this study lies in the use of a nationally representative cohort from the United States. The longitudinal design allowed for the linkage between the dementia status in the previous round and EOL quality measures. Furthermore, the dementia status in this study was determined based on the validated NHATS algorithm. The findings obtained between April 2020 and November 2021 provide insights into the experiences and needs of older adults after long-term restrictions. However, this study had multiple limitations. We did not specify the leading cause of death, including COVID-19, as they were not collected as part of the NHATS. Dementia status and hospice care engagement were not ascertained using fee-for-service Medicare claims data, as the linked claims data were not available for the NHATS 2017 wave and afterward. The quality ratings were based on proxy perceptions, which might have led to a bias based on the acknowledgment of dementia status and the pandemic period. This study

employed regression analyses for all 14 outcome measures; thus, there might be potential for Type I error. Moreover, sampling weights were not applied because the information that was used for oversampling and nonresponse adjustment in the NHATS is not available in the public-use files and differs from round to round.

Conclusions and Implications

Despite these limitations, this is the first study to examine the interaction between dementia status and COVID-19 pandemic on EOL care quality. Our results support the existing need for spiritual care for people with dementia regardless of a health care crisis and restrictions.

References

- Joling KJ, Janssen O, Francke AL, et al. Time from diagnosis to institutionalization and death in people with dementia. *Alzheimers Dement*. 2020;16:662–671.
- Verlinden VJA, van der Geest JN, de Bruijn RFAG, et al. Trajectories of decline in cognition and daily functioning in preclinical dementia. *Alzheimers Dement*. 2016;12:144–153.
- van der Steen JT, Radbruch L, Hertogh CM, et al. White paper defining optimal palliative care in older people with dementia: a Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med*. 2014;28:197–209.
- GBD 2019 Dementia Forecasting Collaborators. Estimation of the global prevalence of dementia in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study 2019. *Lancet Public Health*. 2022;7:e105–e125.
- Sleeman KE, de Brito M, Etkind S, et al. The escalating global burden of serious health-related suffering: projections to 2060 by world regions, age groups, and health conditions. *Lancet Glob Health*. 2019;7:e883–e892.
- Alzheimer's Association. 2022 Alzheimer's disease facts and figures. *Alzheimers Dement*. 2022;18:700–789.
- Davies N, Maio L, Rait G, et al. Quality end-of-life care for dementia: what have family carers told us so far? A narrative synthesis. *Palliat Med*. 2014;28:919–930.
- Luth EA, Prigerson HG. Associations between race and dementia status and the quality of end-of-life care. *J Palliat Med*. 2018;21:970–977.
- Nakanishi M, Nakashima T, Shindo Y, et al. Japanese care location and medical procedures for people with dementia in the last month of life. *J Alzheimers Dis*. 2016;51:747–755.
- Martinsson L, Lundström S, Sundelöf J. Quality of end-of-life care in patients with dementia compared to patients with cancer: a population-based register study. *PLoS One*. 2018;13:e0201051.
- Rossen LM, Nørgaard SK, Sutton PD, et al. Excess all-cause mortality in the USA and Europe during the COVID-19 pandemic, 2020 and 2021. *Sci Rep*. 2022;12:18559.
- COVID-19 Excess Mortality Collaborators. Estimating excess mortality due to the COVID-19 pandemic: a systematic analysis of COVID-19-related mortality, 2020–21. *Lancet*. 2022;399:1513–1536.
- Connolly M, Bell M, Lawler F, et al. Hospital-based palliative and end-of-life care in the COVID-19 pandemic: a scoping review. *Am J Hospice Palliat Med*. 2022;39:1105–1120.
- Ersek M, Smith D, Griffin H, et al. End-of-life care in the time of COVID-19: communication matters more than ever. *J Pain Symptom Manage*. 2021;62(2):213–222.e1.
- Livingston G, Huntley J, Sommerlad A, et al. Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet*. 2020;396:413–446.
- Hua CL, Comell PY, Zimmerman S, et al. Excess Mortality Among Assisted Living Residents With Dementia During the COVID-19 Pandemic. *J Am Med Dir Assoc*. 2022;23:1743–1749.e6.
- Freedman VA, Kasper JD. Cohort profile: The National Health and Aging Trends Study (NHATS). *Int J Epidemiol*. 2019;48:1044–1045g.
- Schrack JA, Freedman VA. *National Health and Aging Trends Study User Guide: Rounds 1-11 Beta Release*. Johns Hopkins University School of Public Health; 2022.
- Kasper J, Freedman V, Spillman B. Classification of persons by dementia status in the national health and aging trends study. NHATS Technical Paper #5. 2013. 1-14. Accessed February 17, 2023. https://www.nhats.org/sites/default/files/2022-09/NHATS%20Dementia%20Classification%20with%20Programming%20Statements_09232022.zip
- Galvin JE, Roe CM, Xiong C, et al. Validity and reliability of the AD8 informant interview in dementia. *Neurology*. 2006;67:1942–1948.
- Weinberger DM, Chen J, Cohen T, et al. Estimation of excess deaths associated with the COVID-19 pandemic in the United States, March to May 2020. *JAMA Intern Med*. 2020;180:1336–1344.
- Teno JM, Clarridge B, Casey V, et al. Validation of toolkit after-death bereaved family member interview. *J Pain Symptom Manage*. 2001;22(3):752–758.
- Kumar V, Ankuda CK, Aldridge MD, et al. Family caregiving at the end of life and hospice use: a national study of Medicare beneficiaries. *J Am Geriatr Soc*. 2020;68:2288–2296.
- Ankuda CK, Kelley AS, Morrison RS, et al. Family and friend perceptions of quality of end-of-life care in medicare advantage vs traditional medicare. *JAMA Netw Open*. 2020;3:e2020345.
- De Vleminck A, Morrison RS, Meier DE, et al. Hospice care for patients with dementia in the United States: a longitudinal cohort study. *J Am Med Dir Assoc*. 2018;19:633–638.
- Xu S, Liu M, Shin O, et al. Differences of quality in end-of-life care across settings: results from the U.S. National Health and Aging Trends Study of Medicare beneficiaries. *J Palliat Med*. 2020;23:1198–1203.
- Harrison KL, Cenzer I, Ankuda CK, et al. Hospice improves care quality for older adults with dementia in their last month of life. *Health Aff*. 2022;41:821–830.
- Cham H, Reshetnyak E, Rosenfeld B, et al. Full information maximum likelihood estimation for latent variable interactions with incomplete indicators. *Multivariate Behav Res*. 2017;52:12–30.
- Ødbehr LS, Hauge S, Danbolt IJ, et al. Residents' and caregivers' views on spiritual care and their understanding of spiritual needs in persons with dementia: a meta-synthesis. *Dementia*. 2017;16:911–929.
- Bolt SR, van der Steen JT, Mujezinović I, et al. Practical nursing recommendations for palliative care for people with dementia living in long-term care facilities during the COVID-19 pandemic: a rapid scoping review. *Int J Nurs Stud*. 2021;113:103781.

Supplementary Table 1

Proportion and 95% CIs of Quality Indicators by Groups of Dementia Status and Period

	Dementia × During Pandemic			Dementia × Before Pandemic			No Dementia × During Pandemic			No Dementia × Before Pandemic		
	Proportion	Lower	Upper	Proportion	Lower	Upper	Proportion	Lower	Upper	Proportion	Lower	Upper
Experienced pain	0.80	0.73	0.86	0.81	0.75	0.86	0.74	0.68	0.80	0.78	0.73	0.83
Unmet need for pain management	0.15	0.10	0.21	0.15	0.10	0.21	0.12	0.08	0.17	0.21	0.16	0.27
Experienced breathing problem	0.55	0.48	0.63	0.63	0.56	0.69	0.54	0.47	0.61	0.62	0.56	0.68
Unmet need for breath	0.09	0.05	0.14	0.15	0.10	0.21	0.12	0.07	0.17	0.15	0.11	0.20
Experienced anxiety or sadness	0.67	0.59	0.74	0.58	0.51	0.65	0.60	0.52	0.67	0.62	0.56	0.68
Unmet need for anxiety or sadness	0.23	0.17	0.31	0.29	0.23	0.36	0.17	0.12	0.24	0.29	0.23	0.35
Decision made without enough input from decedent or family	0.08	0.04	0.12	0.08	0.05	0.13	0.09	0.06	0.14	0.11	0.07	0.15
Decision made that decedent would not have wanted	0.11	0.07	0.17	0.11	0.07	0.16	0.11	0.07	0.16	0.12	0.08	0.17
Family was not always kept informed	0.14	0.09	0.19	0.17	0.12	0.22	0.18	0.14	0.24	0.17	0.12	0.22
Not always treated with respect	0.12	0.08	0.17	0.11	0.07	0.17	0.11	0.07	0.16	0.14	0.10	0.19
Personal care needs not always met	0.20	0.15	0.27	0.21	0.16	0.27	0.17	0.12	0.23	0.21	0.16	0.26
Not always clear with doctor in charge	0.20	0.13	0.29	0.28	0.20	0.36	0.18	0.12	0.27	0.23	0.17	0.30
Did not talk about religion	0.52	0.44	0.60	0.51	0.43	0.59	0.50	0.42	0.58	0.47	0.40	0.53
Overall rating of care was not excellent	0.55	0.48	0.62	0.61	0.54	0.68	0.51	0.44	0.57	0.56	0.49	0.62

Higher proportion means lower care quality.

Supplementary Table 2

Adjusted OR and 95% CIs of Quality Indicators by the Main Effects of Dementia Status and Period

	Dementia			Pandemic		
	OR	CI, Lower	CI, Upper	OR	CI, Lower	CI, Upper
Experienced pain	0.745	0.513	1.081	1.150	0.832	1.588
Unmet need for pain management	0.973	0.629	1.504	0.793	0.543	1.159
Experienced breathing problem	0.738	0.545	1.001	1.101	0.846	1.432
Unmet need for breath	0.983	0.609	1.587	0.910	0.596	1.389
Experienced anxiety/sadness	1.169	0.849	1.608	1.144	0.868	1.507
Unmet need for anxiety/sadness	0.843	0.580	1.225	1.227	0.885	1.701
Decision made without enough input from decedent or family	0.921	0.544	1.560	0.877	0.556	1.383
Decision made that decedent would not have wanted	1.179	0.731	1.903	1.010	0.659	1.549
Family was not always kept informed	1.022	0.702	1.488	1.252	0.907	1.728
Not always treated with respect	0.942	0.595	1.490	1.093	0.738	1.618
Personal care needs not always met	1.084	0.726	1.619	0.904	0.640	1.277
Not always clear with doctor in charge	0.787	0.495	1.254	1.208	0.808	1.805
Did not talk about religion	1.470*	1.037	2.084	1.120	0.827	1.518
Overall rating of care was not excellent	0.839	0.621	1.135	1.298*	1.002	1.680

OR, odds ratio.

OR higher than 1.00 means lower care quality.

Full information maximum likelihood method was used (N = 1050).

The binomial logistic regression model included age at death, sex, race/ethnicity, proxy relationship to the decedent, proxy sex, place of residence, and use of hospice care within the last month of life as covariates.

*P value < .05.

Supplementary Table 3

Adjusted OR and 95% CIs of Quality Indicators by the Main Effects of Dementia, Pandemic, and Interaction Between Dementia and Pandemic

	Dementia			Pandemic			Dementia × Pandemic		
	OR	CI, Lower	CI, Upper	OR	CI, Lower	CI, Upper	OR	CI, Lower	CI, Upper
Experienced pain	0.690	0.426	1.118	1.059	0.668	1.678	1.188	0.593	2.384
Unmet need for pain management	0.735	0.414	1.305	0.613	0.369	1.020	1.884	0.836	4.244
Experienced breathing problem	0.711	0.476	1.063	1.058	0.729	1.536	1.088	0.616	1.921
Unmet need for breath	1.133	0.610	2.106	1.024	0.602	1.742	0.722	0.295	1.770
Experienced anxiety/sadness	0.958	0.629	1.458	0.942	0.643	1.381	1.547	0.850	2.818
Unmet need for anxiety/sadness	0.709	0.424	1.187	1.070	0.696	1.644	1.409	0.700	2.836
Decision made without enough input from decedent or family	0.855	0.431	1.696	0.818	0.435	1.538	1.172	0.442	3.105
Decision made that decedent would not have wanted	1.035	0.546	1.959	0.894	0.499	1.601	1.312	0.546	3.153
Family was not always kept informed	0.911	0.545	1.522	1.129	0.721	1.768	1.259	0.629	2.518
Not always treated with respect	0.880	0.432	1.482	0.935	0.539	1.624	1.410	0.604	3.290
Personal care needs not always met	1.234	0.735	2.073	1.037	0.637	1.688	0.746	0.355	1.567
Not always clear with doctor in charge	0.841	0.445	1.591	1.263	0.760	2.099	0.880	0.371	2.091
Did not talk about religion	1.550	0.972	2.473	1.181	0.769	1.814	0.894	0.466	1.716
Overall rating of care was not excellent	0.809	0.543	1.205	1.252	0.862	1.818	1.080	0.614	1.899

OR, odds ratio.

OR higher than 1.00 means lower care quality.

Full information maximum likelihood method was used (N = 1050).

The binomial logistic regression model included age at death, sex, race/ethnicity, proxy relationship to the decedent, proxy sex, place of residence, and use of hospice care within the last month of life as covariates.