

NIH Public Access

Author Manuscript

Med Care. Author manuscript; available in PMC 2013 October 01.

Published in final edited form as:

Med Care. 2012 October ; 50(10): 856-862. doi:10.1097/MLR.0b013e31825dd713.

The Quality of Advanced Dementia Care in the Nursing Home: The Role of Special Care Units

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Abstract

Background—The quality of nursing home care for residents with advanced dementia has been described as suboptimal. One relatively understudied factor is the impact of special care units (SCUs) for dementia for residents at the end-stage of this disease.

Objective—To examine the association between residence in an SCU and the quality of end-of-life care for nursing home residents with advanced dementia.

Research Design—This study employed longitudinal data on 323 nursing home residents with advanced dementia living in 22 Boston-area facilities. Using multivariate methods, we analyzed the association between residence in an SCU and measures of quality of end-of-life care including: treatment of pain and dyspnea, prevalence of pressure ulcers, hospitalization, tube feeding, antipsychotic drug use, advance care planning, and health care proxy (HCP) satisfaction with care.

Results—A total of 43.7% residents were cared for in an SCU. After multivariate adjustment, residents in SCUs were more likely to receive treatment for dyspnea, had fewer hospitalizations, were less likely to be tube fed, and more likely to have a do-not-hospitalize order, compared to non-SCU residents. However, non-SCU residents were more likely to be treated for pain, had fewer pressure ulcers, and less frequent use of antipsychotic drugs than SCU residents. HCPs of SCU residents reported greater satisfaction with care than HCPs of non-SCU residents.

Conclusions—Residence in an SCU is associated with some, but not all, markers of better quality end-of-life care among nursing home residents with advanced dementia.

Keywords

special care units; quality of care; dementia; end-of-life care

INTRODUCTION

Dementia is a complex disorder affecting memory, cognition, and behavior, associated with decline in quality of life and increased risk of institutionalization. The prevalence of dementia among adults over 70 is estimated to be 14%.¹ Approximately half of adults with dementia reside in nursing homes or assisted living facilities,² and approximately 70% of Americans with dementia will die in a nursing home.³

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Nursing home residents in the final stages of dementia are totally functionally dependent, have profound memory loss, are bed-bound, incontinent of urine, and have limited verbal ability (five words or less). Providing care to these residents requires knowledge and skills specific to the medical, physical, cognitive, and supportive needs of this patient population and their families. Over the past decade, there has been a rise in dementia special care units (SCUs), specialized units within nursing homes where the structural design, staffing, and activity programs are intended to provide a supportive social and prosthetic physical environment for residents with dementia.² With approximately 2,800 units nationwide in 2008, SCUs are a very common form of specialized long-term care. Three times as many dementia SCUs exist in the U.S. compared to rehabilitation units, the second most common type of specialized care.⁴ Past studies have found that SCU residence is positively associated with several long-term care quality indicators, including less frequent tube feeding,⁵ less use of physical restraints,^{6, 7} lower risk of pressure ulcers,⁸ better continence care,^{4, 8} fewer behavioral disturbances,⁴ lower risk of hospitalization,⁷ and higher quality of life.²

Although a modest body of evidence has examined the impact of SCUs on dementia care,⁹ less is known regarding the value of specialized units in the care of persons with advanced dementia. Nursing home residents with advanced dementia have special needs, particularly related to palliative care, and past research indicates that the terminal care for this population is often inadequate. Compared to other terminally ill nursing home residents, prior studies have found that residents with dementia are less likely to receive adequate pain control,¹⁰ more likely to suffer from neglect,¹¹ more likely to be subject to burdensome interventions, less likely to have advance directives limiting aggressive care,¹² and less likely to be referred to hospice.^{13, 14} Given the special needs of nursing home residents with advanced dementia, SCUs may provide particular value to this group. In prior work, SCU residence has been associated with greater satisfaction with care among health care proxies for nursing home residents with advanced dementia.¹⁵

In order to examine the quality of advanced dementia care received in SCUs compared to the quality of care received in non-specialized nursing home units, we employed data from the CASCADE study (Choices, Attitudes, Strategies, and Care for Advanced Dementia at the End-of-Life), a large prospective cohort study of nursing home residents with advanced dementia and their health care proxies.¹⁶

METHODS

Study Sample

The present investigation used longitudinal data collected as part of the CASCADE study, a prospective cohort study of 323 nursing home residents with advanced dementia and their health care proxies (HCPs) in 22 Boston-area facilities.³ A detailed description of the CASCADE study design is provided elsewhere.³

Participating facilities were required to have at least 60 beds and be located within a 60-mile radius of Boston. To be eligible, nursing home residents had to have advanced dementia, as defined by: (1) a diagnosis of dementia (any type) determined by chart review; and (2) a Global Deterioration Scale (GDS) score of 7 determined by nurse interview. GDS stage 7 is characterized by very severe cognitive decline, minimal to no verbal communication, dependence in eating and toileting, incontinence of urine and stool, and loss of the ability to walk.¹⁷ Additional eligibility criteria included (1) being age of 60 years or older, (2) a length of nursing home stay of 30 days or longer, and (3) an appointed HCP who could communicate in English. HCPs provided informed consent for their participation and that of the residents.

Resident data were drawn from assessments that included a chart review, a nursing interview, and a brief clinical examination, and were conducted at baseline and quarterly for up to 18 months or until death. Telephone interviews with HCPs were conducted at baseline and quarterly for up to 18 months. If residents died, a resident assessment and HCP interview were conducted around the time of death. However, because the immediate dying process is unique in terms of quality of care variables, data from these death assessments were excluded from our analyses.

Whether or not residents were cared for in an SCU was ascertained at baseline. As previous studies have found that dementia treatment may vary based not only on whether the resident is in an SCU, but also on whether the facility has an SCU,^{18, 19} residents were classified by their proximity to an SCU, into three categories: (1) in an SCU, (2) not in an SCU but residing in a facility that had an SCU, and (3) in a facility that did not have an SCU. We verified whether facilities had an SCU using data from the Online Survey, Certification, and Reporting (OSCAR) system.

End-of-Life Quality Measures

Five domains of long-term care quality specific to advanced dementia were identified: (1) treatment of distressing symptoms (pain and dyspnea), (2) pressure ulcers; (3) burdensome interventions, (4) advance care planning, and (5) HCP satisfaction with care. The variables included eight well-established measures of long-term care quality for older adults with end-stage dementia within these five domains.²⁰, 21, 22, 23

Treatment of pain was defined as whether or not residents who experienced pain on five or more days per month received scheduled oral or parenteral (intravenous, subcutaneous, transdermal, or sublingual) opioids. Treatment of dyspnea was defined as whether or not residents who had difficulty breathing on five or more days per month received treatment with oxygen, morphine, scopolamine, or hyoscyamine.

Whether or not residents had stage 2 or higher pressure ulcers was ascertained from nurse interview at each assessment.

Burdensome interventions included whether or not the resident had a percutaneous endoscopic gastrostomy (PEG) tube, whether or not the resident was administered any antipsychotic medications in the prior 90 days, and whether or not the resident experienced at least one hospital transfer (hospitalization or emergency room visit) in the prior 90 days.

Advance care planning data included whether or not the resident had a do-not-hospitalize (DNH) order.

Finally, HCPs' satisfaction with care was ascertained at baseline and follow-up interviews using the Satisfaction with Care at the End-of-Life in Dementia (SWC-EOLD) Scale (ranging from 10 to 40, with higher scores indicating greater satisfaction).^{22, 23}

Certain variables were point-in-time measures determined at the baseline assessment and all other follow-up assessments (pressure ulcers, DNH order, and SWC-EOLD). Other measures reflected events that occurred in the three months since the prior quarterly assessment (treatment of pain, treatment of dyspnea, hospitalization, tube feeding, and antipsychotic drug use), and therefore were not measured at baseline.

Other Variables

Baseline resident characteristics included: age, gender, race (white vs. non-white), marital status (married vs. unmarried, widowed, or divorced), education (completed high school vs.

did not complete high school) and residence directly prior to nursing home admission (private residence vs. hospital, another nursing home, or assisted living). Functional status was determined using the Bedford Alzheimer's Nursing Severity-Subscale (BANS-S) (range, 7-28 with higher scores indicating more functional disability).²⁰

Baseline HCP characteristics included: age, gender, and relationship to resident (child vs. other). At each interview, HCPs were asked whether they viewed comfort as the primary goal of care, and whether they thought dementia was a terminal illness. For observations where HCP attitudes and beliefs about dementia were missing, values were imputed based on the prior observation.

Statistical Analysis

The main independent variable for all analyses was whether or not the resident lived in an SCU at baseline. As non-SCU units in nursing homes with an SCU may differ from non-SCU units in nursing homes without an SCU, we compared outcomes across these three groups. The unit of analysis was the multiple assessments conducted during the entire 18-month follow-up period, with non-dynamic resident and HCP characteristics (e.g., gender) carried forward, and dynamic variables taken from the same assessment as the outcome variables. Treatment of pain, treatment of dyspnea, pressure ulcers, PEG tube placement, receipt of antipsychotic drugs, hospitalization, presence of a DNH order, and HCP satisfaction with care were examined as outcomes.

Baseline resident characteristics were described using means for continuous variables and proportions for categorical variables. Resident and HCP baseline characteristics were compared for residents in an SCU ("SCU"), residents not in an SCU but in a facility with an SCU ("non-SCU"), and residents in a facility without an SCU ("no SCU") using unadjusted logistic regression.

In addition to the baseline resident and HCP covariates, all models were adjusted for whether the resident experienced pneumonia, febrile illness, or another sentinel event since the previous assessment, and whether the resident had been referred to hospice in the past 90 days. The models examining treatment of pain and dyspnea were limited to observations where symptoms were reported five or more days per month in the 90 days prior to the assessment. The frequency with which the resident experienced these symptoms was included as a covariate in these models (rarely vs. sometimes/often/almost daily). The antipsychotic drugs model was further adjusted based on whether the resident had experienced agitation in the past 90 days and whether or not the resident had a baseline diagnosis of psychiatric illness (depression, schizophrenia, or other major psychiatric condition).

All models were estimated using multivariate logistic regression, except for the model examining SWC-EOLD as an outcome, which was estimated using ordinary least squares regression. We included quarter-year fixed effects to account for any unobserved time trends in our outcomes, and clustered robust standard errors at the facility-unit level. Residents in an SCU served as the reference group for all analyses.

RESULTS

Among the 1,763 nursing home residents screened for the study, 570 (32.3%) residents met eligibility criteria. Among those eligible, 323 (56.7%) residents with advanced dementia and their HCPs were recruited into the study and included in these analyses (HCP refusal was the sole reason for non-participation). In addition to the 323 baseline assessments, 1,669

follow-up assessments were obtained during the course of the study, for a total of 1,992 assessments available for analysis.

Baseline Characteristics and SCU Status

Among the total resident sample (N=323), the mean age was 85.3 years, 85.4% were female, 89.5% were white, 19.8% were married, and 77.4% completed high school. 29.7% were admitted to the nursing home from a private residence. The average BANS-S score was 21.0 (SD = 2.3), reflecting a high level of functional disability. As shown in Table 1, 43.7% of residents were living in an SCU at baseline. SCU residents were significantly younger than non-SCU residents (the mean age in SCUs was 84.1, versus 85.7 and 88.8 for non-SCU and no SCU residents, respectively). SCU residents were also significantly more likely to have been admitted to the nursing home from a private residence than non-SCU residents (34.8% versus 25.8%). Residents in a facility without an SCU were less likely to be white than residents in an SCU (67.7% versus 91.5%).

Table 1 also presents HCP baseline characteristics. The mean age of HCPs was 59.9 years, 63.8% were female, 67.8% were married, and 57.3% completed college. 67.5% were the child of a resident. The HCPs' marital status and education did not differ based on SCU status. However, HCPs of SCU residents were significantly younger than HCPs of non-SCU residents (the mean age in an SCU was 58.4 versus 60.9 and 62.2 for non-SCU and no SCU residents, respectively). HCPs of SCU residents were more likely to be female than HCPs of non-SCU residents (66.0% versus 58.3%), and less likely to be female than HCPs of residents in a facility without an SCU (80.7%). HCP relationship also varied between SCU and non-SCU residents, with children serving as HCPs for 73.0% of SCU residents, compared to 62.9% of non-SCU residents and 64.5% of residents in a facility without an SCU.

End-of-Life Quality Outcomes

Pain was significantly more likely to be treated among non-SCU residents compared to SCU residents, both in facilities with an SCU (OR=1.07; 95% CI=1.04, 1.10) and facilities without an SCU (OR=2.43; 95% CI=1.26, 4.70). However, dyspnea was less likely to be treated among non-SCU residents compared to SCU residents, both in facilities with an SCU (OR=0.453, 95% CI=0.40, 0.52) and facilities without an SCU (OR=0.25, 95% CI=0.19, 0.33).

Incidence of pressure ulcers was significantly lower among non-SCU residents in facilities with an SCU than SCU residents (OR=0.74, 95% CI=0.73, 0.75). No difference in the incidence of pressure ulcers was found between SCU residents and residents in a facility without an SCU.

The odds of hospitalization were significantly higher among non-SCU residents compared to SCU residents, both in facilities with an SCU (OR=2.36, 95% CI=2.24, 2.49) and facilities without an SCU (OR=2.45, 95% CI=1.52, 3.93). The likelihood of being tube fed was significantly higher among non-SCU residents in facilities with an SCU (OR=2.87, 95% CI=3.62, 4.13), while the use of antipsychotic drugs was significantly lower (OR=0.61, 95% CI=0.57, 0.66). Residents in a facility without an SCU did not differ from SCU residents on either of these outcomes.

Non-SCU residents in facilities with an SCU were significantly less likely than SCU residents to have a DNH order (OR=0.54; 95% CI=0.52, 0.56). Residents in a facility without an SCU did not differ from SCU residents in the incidence of DNH orders.

HCPs of non-SCU residents reported significantly lower satisfaction with care than HCPs of SCU residents, both in facilities with an SCU (Coefficient=-1.49; 95% CI=-1.55, -1.42) and in facilities without an SCU (Coefficient=-1.88, 95% CI=-3.15, -0.60).

DISCUSSION

Although past studies have examined the impact of SCUs on dementia care, this is the first report looking at the effect of SCUs on the quality of care of persons with advanced dementia. Roughly half of the nursing home residents observed in the present study resided in an SCU. We found that SCU residents received higher quality end-of-life care in several areas, including better treatment of dyspnea, less tube feeding, fewer hospitalizations, greater likelihood of having a DNH order, and greater HCP satisfaction with care. At the same time, several quality measures were less favorable among the residents in SCUs, including treatment of pain, incidence of pressure ulcers, and use of antipsychotic drugs.

Compared to other terminally ill nursing home residents, prior studies have found that residents with dementia are less likely to receive adequate pain control,¹⁰ and more likely to suffer from neglect.¹¹ Although treatment of dyspnea was better among SCU residents compared to non-SCU residents, we found that treatment of pain was worse. We did observe a greater frequency in reports of pain among non-SCU residents compared to SCU residents, suggesting that perhaps nursing home residents with certain co-morbidities associated with pain are more likely to be admitted to a general nursing home unit than an SCU. Identifying how to ensure that nursing home residents with advanced dementia receive adequate treatment of pain is an important area for future exploration.

Compared to other terminally ill nursing home residents, prior studies have found that residents with dementia are more likely to be subject to burdensome interventions and less likely to have advance directives limiting aggressive care.¹² We found that two burdensome interventions –tube feeding and hospitalization - were significantly less common among SCU residents compared to non-SCU residents. We observed greater use of antipsychotic drugs among SCU residents compared to non-SCU residents, even after controlling for agitation and baseline diagnosis of psychiatric illness. These findings are consistent with past studies reporting higher national rates of antipsychotic drug use in SCUs.^{4, 24}, Residents with particular behavioral health needs identified at the time of nursing home entry may be more likely to be admitted to an SCU, thus explaining the higher rate of antipsychotic drug use observed among this population.

In addition to SCU residence, we were also interested in whether proximity to an SCU influenced quality of care. A prior survey of Minnesota nursing homes found that SCUs were more likely to report staff training programs and environmental modifications than non-specialized units. However, program types identified as "dementia-specific" were no more prevalent in SCUs than non-specialized units. The authors speculated that some nursing homes might treat SCUs as laboratories for developing practices to expand to other units within the facility, while others may view the SCU as a place to contain residents who may cause disturbances if integrated in the general nursing home population.¹⁸ Our findings show that quality of care for non-SCU residents was consistently associated with proximity to an SCU, although the direction of this association was not always consistent. Specifically, non-SCU residents in facilities with SCUs had worse treatment of pain, were more likely to be tube fed, and were less likely to have a DNH order than their counterparts in facilities without SCUs. Conversely, non-SCU residents in facilities with SCUs had better treatment of dyspnea and were less likely to experience pressure ulcers. These findings suggest that future research on SCUs should take into consideration the potential externalities—both positive and negative of-specialized care on other nursing home residents.

Several limitations apply to our analyses. The CASCADE study included residents of nursing homes in the greater Boston area, the geographic and socioeconomic homogeneity of which may restrict the external validity of the results. Although information was not available on residents and families who chose not to participate, the study population and facilities are comparable to those nationwide.³

Although we controlled for a number of resident and HCP characteristics, additional unobserved variables may have influenced SCU admission. Additionally, there may be differences between facilities in terms of size, ownership status, and chain membership, all potentially contributing to bias in our results. Although our data are not powered to examine facility-level issues, they provide several important advantages over larger administrative databases including: 1) specific focus on a population with advanced dementia; 2) detailed outcome data specific to this population; and 3) detailed data on health care proxies and their attitudes and beliefs about care.

Moreover, we faced the broader challenge of how best to measure quality of long-term care, particularly for the terminally ill. Unlike acute care for which successful outcomes mean restoring patients to their level of functioning prior to onset of illness, successful outcomes of long-term care can be difficult to ascertain, and as a result, structure and process factors are commonly used to measure quality. Frequently employed indicators include: use of physical and chemical restraints; prevalence of pressure sores; prevalence of malnutrition and dehydration; continence care; pain management; and hospitalization.²⁵ However, it is unclear whether these indicators are appropriate for evaluating quality of end of life care for persons with advanced dementia. For example, although many would consider tube feeding a burdensome intervention for a nursing home resident with advanced dementia (as we did), federal nursing home regulations encourage interventions to prevent weight loss.²⁶ For the present study, we explored a compendium of potential outcome variables, and selected those we felt best represented a complete picture of the quality of end-of-life care for nursing home residents with advanced dementia. However, future work is needed to more extensively identify and validate quality measures and metrics for this population.

Finally, the criteria for SCU designation are not clearly defined. Many nursing homes with SCUs report higher staffing ratios, specialized staff training, prosthetic environmental features, and enhanced programs. However, we lack both a standard definition of an SCU, and structural criteria for what such a designation entails. This lack of standardization presents evaluative challenges, but our hope is that the present study will offer some guidance as to how SCUs can be improved to better serve nursing home residents with advanced dementia. It is possible that the lack of a standardized definition of an SCU may have biased our results towards the null, as the SCU and non-SCU groups may be more similar than that they would have been had stricter criteria been applied. If this is the case, the true effects of SCU residence and proximity are potentially more robust than our findings indicate. Additionally, we ascertained SCU status at baseline only. Though unlikely, it is possible that nursing home residents moved into or out of SCUs over the course of the study period, which would also potentially bias our results towards the null.

With the elderly population in the U.S. expected to double from approximately 35 million in 2006 to more than 70 million by 2030,²⁷ efforts to improve advanced dementia care provided in nursing home settings may result in significant improvements to the quality of life for the 4.5 million older Americans with Alzheimer's disease or related dementias.¹⁰ Our findings suggest residence in an SCU is associated with some, but not all, markers of better quality end-of-life care among nursing home residents with advanced dementia.

Acknowledgments

Sources of Support: This project was supported by NIH-NIA R01 AG024091. Ms. Cadigan would like to acknowledge support from an AHRQ pre-doctoral National Research Service Award. Dr. Givens is supported by NIH-NIA K23 AG034967. Dr. Mitchell is supported by NIH-NIA K24 AG033640.

References

- Plassman BL, Langa KM, Fisher GG, Heeringa SG, Weir DR, Ofstedal MB, Burke JR, Hurd MD, Potter GG, Rodgers WL, Steffens DC, Willis RJ, Wallace RB. Prevalence of Dementia in the United States: The Aging, Demographics, and Memory Study. Neuroepidemiology. 2007; 29:125– 132. [PubMed: 17975326]
- Reimer MA, Slaughter S, Donaldson C, Currie G, Eliasziw M. Special Care Facility Compared with Traditional Environments for Dementia Care: A Longitudinal Study of Quality of Life. J Am Geriatr Soc. 2004; 52:1085–1092. [PubMed: 15209645]
- Mitchell SL, Kiely DK, Jones RN, Prigerson H, Volicer L, Teno JM. Advanced Dementia Research in the Nursing Home: The CASCADE Study. Alzheimer Dis Assoc Disord. 2006; 20:166–175. [PubMed: 16917187]
- Bellelli G, Frisoni GB, Bianchetti A, Boffelli S, Guerrini GB, Scotuzzi A, Ranieri P, Ritondale G, Guglielmi L, Fusari A, Raggi G, Gasparotti A, Gheza A, Nobili G, Trabucchi M. Special Care Units for Demented Patients: A Multicenter Study. Gerontologist. 1998; 38(4):456–462. [PubMed: 9726132]
- Lamberg JL, Person CJ, Kiely DK, Mitchell SL. Decisions to Hospitalize Nursing Home Residents Dying with Advanced Dementia. J Am Geriatr Soc. 2005; 53:1396–1401. [PubMed: 16078968]
- 6. Gruneir A, Lapane KL, Miller SC, Mor V. Is Dementia Special Care Really Special? A New Look at an Old Question. JAGS. 2008; 56:199–205.
- Nobili A, Piana I, Balossi L, Pasina L, Matucci M, Tarantola M, Trevisan S, Rive E, Lucca U, Tettamanti M. Alzheimer Special Care Units Compared with Traditional Nursing Home for Dementia Care: Are There Differences at Admission and in Clinical Outcomes? Alzheimer Dis Assoc Disord. 2008; 22(4):352–361. [PubMed: 18978601]
- Luo H, Fang X, Liao Y, Elliott A, Zhang X. Associations of Special Care Units and Outcomes of Residents with Dementia: 2004 National Nursing Home Study. Gerontologist. 2010; 50(4):509– 518. [PubMed: 20462932]
- 9. Lai CKY, Yeung JHM, Mok V, Chi I. Special Care Units for Dementia Individuals with Behavioral Problems. Cochrane Database of Systematic Reviews. 2009; (4) Art. No.: CD006470.
- 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; 50:507–515. [PubMed: 11943048]
- Kayser-Jones J. The Experience of Dying: An Ethnographic Nursing Home Study. Gerontologist. 2002; 42(S3):11–19. [PubMed: 12415128]
- Mitchell SL, Kiely DK, Hamel MB. Dying with Advanced Dementia in the Nursing Home. Arch Intern Med. 2004; 164:321–326. [PubMed: 14769629]
- 13. Casarett DJ, Hirschman KB, Henry MR. Does Hospice Have a Role in Nursing Home Care at the End of Life? J Am Geriatr Soc. 2001; 49:1493–1498. [PubMed: 11890588]
- Christakis NA, Escarce JJ. Survival of Medicare Patients after Enrollment in Hospice Programs. N Engl J Med. 1996; 335:172–178. [PubMed: 8657216]
- Engel SE, Kiely DK, Mitchell SL. Satisfaction with End-of-Life Care for Nursing Home Residents with Advanced Dementia. J Am Geriatr Soc. 2006; 54:1567–1572. [PubMed: 17038076]
- Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN, Prigerson HG, Volicer L, Givens JL, Hamel MB. The Clinical Course of Advanced Dementia. N Engl J Med. 2009; 361(16):1529– 1538. [PubMed: 19828530]
- Reisberg B, Ferris SH, de Leon MJ, et al. The Global Deterioration Scale for Assessment of Primary Degenerative Dementia. Am J Psychiatry. 1982; 139:1136–1139. [PubMed: 7114305]

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- Grant LA, Kane RA, Stark AJ. Beyond Labels: Nursing Home Care for Alzheimer's Disease In and Out of Special Care Units. J Am Geriatr Soc. 1995; 43(5):569–576. [PubMed: 7730542]
- Gruneir A, Lapane KL, Miller SC, Mor V. Does the Presence of a Dementia Special Care Unit Improve Nursing Home Quality? J Aging Health. 2008; 20(7):837–854. [PubMed: 18815412]
- Lynn J. Measuring Quality of Care at the End of Life: A Statement of Principles. J Am Geriatr Soc. 1997; 45:526–527. [PubMed: 9100727]
- 21. Teno JM, Landrum K, Lynn J. Defining and Measuring Outcomes in End-Stage Dementia. Alzheimer Dis Assoc Disord. 1997; 11(Suppl 6):25–29. [PubMed: 9437445]
- 22. Volicer L, Hurley AC, Blasi ZV. Scales for Evaluation of End-of-Life Care in Dementia. Alzheimer Dis Assoc Disord. 2001; 15:194–200. [PubMed: 11723370]
- Kiely DK, Volicer L, Teno J, et al. The Validity and Reliability of Scales for the Evaluation of End-of-Life Care in Advanced Dementia. Alzheimer Dis Assoc Disord. 2006; 20:176–181. [PubMed: 16917188]
- Phillips CD, Spry KM, Sloane PD, Hawes C. Use of Physical Restraints and Psychotropic Medications in Alzheimer Special Care Units in Nursing Homes. Am J Public Health. 2000; 90:92–96. [PubMed: 10630143]
- 25. Institute of Medicine. Improving the Quality of Long-Term Care. Washington, DC: National Academy of Sciences; 2001.
- Genao L, White H, Twersky J. Correspondence: The Clinical Course of Advanced Dementia. N Engl J Med. 2010; 362(4):363–365. [PubMed: 20112444]
- 27. Federal Interagency Forum on Aging-Related Statistics. Federal Interagency Forum on Aging-Related Statistics. Washington, DC: U.S. Government Printing Office; Mar. Older Americans 2008: Key Indicators of Well-Being. Available at: http://www.egingstate.gov/Agingstatedetate/Wain_Site/Deta/2008_Deguments/OA_2008_pdf

http://www.agingstats.gov/Agingstatsdotnet/Main_Site/Data/2008_Documents/OA_2008.pdf

Table 1

Baseline Resident and Health Care Proxy Characteristics by SCU Status

Resident Characteristics			
Variable	All Residents	By SCU Status	p-value
		Non-SCU: 151	
Total Residents	323	<i>SCU:</i> 141	
		<i>No SCU:</i> 31	
		Non-SCU: 85.7 (7.4)	0.001
Mean Age (SD)	85.3 (7.5)	SCU: 84.1 (7.5)	
		No SCU: 88.8 (6.5)	0.001
		Non-SCU: 84.1%	0.027
Female	85.4%	<i>SCU:</i> 87.9%	
		No SCU: 80.7%	0.119
		Non-SCU: 92.1%	0.780
White	89.5%	SCU: 91.5%	
		<i>No SCU:</i> 67.7%	0.001
		Non-SCU: 17.9%	0.233
Married	19.8%	SCU: 23.4%	
		No SCU: 12.9%	0.315
		Non-SCU: 76.2%	0.004
Completed High School	77.4%	SCU: 82.0%	
		No SCU: 62.1%	0.001
		Non-SCU: 25.8%	0.001
Admitted to NH from Private Home/Apt	29.7%	<i>SCU:</i> 34.8%	
		<i>No SCU:</i> 25.8%	0.052
		Non-SCU: 21.4	0001
Mean BANS-S Score	21.0	SCU: 21.1	
		No SCU: 21.7	0.690
Health Care Proxy Characteristics			
Variable	All Residents	By SCU Status	p-value
		Non-SCU: 60.9 (12.8)	0.001
Mean Age (SD)	59.9 (11.6)	SCU: 58.4 (10.4)	
		No SCU: 62.2 (10.8)	0.001
		Non-SCU: 58.3%	0.037
Female	63.8%	<i>SCU:</i> 66.0%	
		No SCU: 80.7%	0.003

Resident Characteristics			
Variable	All Residents	By SCU Status	p-value
		Non-SCU: 72.2%	0.566
Married/Living with Partner	67.8%	SCU: 64.5%	
		<i>No SCU:</i> 61.3%	0.929
		Non-SCU: 62.9%	0.007
Child of Resident	67.5%	SCU: 73.0%	
		<i>No SCU:</i> 64.5%	0.040
		Non-SCU: 58.9%	0.816
Completed College	57.3%	<i>SCU:</i> 58.9%	
		No SCU: 41.9%	0.349

SCU = residents in a dementia special care unit (SCU); non-SCU = residents not in a dementia special care unit, but in a facility with an SCU; no SCU = residents not in a facility with an SCU. Residents in an SCU served as the reference group for all analyses.

Ordinary least squares regression used to compare means, logistic regression used to compare frequencies.

BANS-S = Bedford Alzheimer's Nursing Severity-Subscale (ranges from 7-28, with higher scores indicating more functional disability.

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Table 2

Association between SCU Proximity and Quality Outcome Measures among Nursing Home Residents with Advanced Dementia

Outcome	Frequency of Outcomes	: Instances/Total Obs (%)	Unadjus	ted Results	Adjust	ed Results
			Odds Ratio	(95% CI)	Odds Ratio	(95% CI)
	Non-SCU:	49/222 (22.1)	0.895	(0.562, 1.423)	1.071^{**}	(1.042, 1.100)
Treatment of Pain $\dot{\tau}$	SCU:	44/183 (24.0)				
	No SCU:	8/27 (29.6)	1.330	(0.545, 3.249)	2.434 **	(1.260, 4.703)
	Non-SCU:	114/186 (61.3)	0.568*	(0.359, 0.900)	0.453**	(0.397, 0.517)
Treatment of Dyspnea [‡]	SCU:	117/159 (73.6)			-	
	No SCU:	23/37 (62.2)	0.590	(0.278, 1.251)	0.251^{**}	(0.191, 0.329)
	Non-SCU:	84/836 (10.1)	0.791	(0.577, 1.083)	0.743 **	(0.732, 0.754)
Pressure Ulcers	SCU:	91/735 (12.4)				
	No SCU:	22/146 (15.1)	1.256	(0.759, 2.078)	1.292	(0.897, 1.862)
	Non-SCU:	91/836 (10.9)	2.870**	(1.876, 4.392)	2.868**	(3.622, 4.129)
Tube Feeding	SCU:	30/735 (4.1)			-	
	No SCU:	7/146 (4.8)	1.183	(0.510, 2.748)	0.685	(0.314, 1.497)
	Non-SCU:	117/836 (14.0)	0.680^{**}	(0.520, 0.888)	0.613^{**}	(0.572, 0.656)
Antipsychotic Drugs ${}^{\varPsi}$	SCU:	142/735 (19.3)		-	1	-
	No SCU:	16/146 (11.0)	0.514 *	(0.296, 0.891)	0.753	(0.235, 2.414)
	Non-SCU:	62/836 (7.4)	2.023**	(1.280, 3.197)	2.363 **	(2.242, 2.491)
Hospital Transfer	SCU:	28/735 (3.8)			-	
	No SCU:	13/146 (8.9)	2.468	(1.246, 4.881)	2.447 **	(1.524, 3.928)
	Non-SCU:	419/955 (43.9)	0.707	(0.588, 0.851)	0.539^{**}	(0.520, 0.559)
DNH Order	SCU:	452/861 (52.5)	-	1	1	-
	No SCU:	76/176 (46.3)	0.688^{*}	(0.496, 0.954)	0.936	(0.585, 1.499)

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Outcome	Frequency of Outcome	s Instances/Total Obs (%)	Unadjus	ted Results	Adjust	ed Results
			Odds Ratio	(95% CI)	Odds Ratio	(95% CI)
	Non-SCU:	31.8 (4.6)	-1.176**	(-1.675, -0.677)	-1.485 **	(-1.547, -1.423)
SWC-EOLD	SCU:	33.0 (4.3)				
	No SCU:	30.5 (4.8)	-2.462 **	(-3.403, -1.520)	-1.875*	(-3.149,-0.601)

SCU = residents in a dementia special care unit (SCU); non-SCU = residents not in a dementia special care unit, but in a facility with an SCU; no SCU = residents not in a facility with an SCU. an SCU served as the reference group for all analyses.

dementia is terminal; whether HCP believes comfort is primary goal of care; occurrence of pneumonia, febrile illness or sentinel event in 90 days prior to assessment; referral to hospice in the 90 days prior Adjusted models controlling for the resident's age, gender, race, functional status, and place of residence prior to admission to NH; HCP age, gender, and relationship to resident; whether HCP understands to assessment; and a quarter-year fixed effect. Robust standard errors were clustered at the facility-unit level. All models were estimated using logistic regression except for the SWC-EOLD model, which was estimated using least squares (and means [standard deviations] were presented instead of frequencies for this outcome). The logistic regression results are presented as odds ratios, while the OLS regression results are presented as coefficients.

 $\dot{\tau}$. Treatment of pain also controlling for pain severity. Limited to observations where the resident had 5 days of pain in the 90 days prior to assessment.

 $\frac{1}{2}$ Treatment of dyspnea also controlling for dyspnea severity. Limited to observations where the resident had 5 days of dyspnea in the 90 days prior to assessment.

f Antipsychotic drugs also controlling for baseline diagnosis of psychiatric illness; whether the resident experienced agitation in the 90 days prior to assessment.

= statistically significant at 5% level;

** = statistically significant at 1% level. DNH = Do Not Hospitalize, HCP = Health Care Proxy, SWC-EOLD = Satisfaction with Care at the End-of-Life in Dementia Scale (ranges from 10-40, with higher scores indicating greater satisfaction).