

Dignity At The End Of Life: Environmental And Structural Drivers Of Hospice Care Quality In Dementia:

Romon Thach OMS-IV, Carlisle St Martin MD
Nova Southeastern University Dr. Kiran C. Patel College of Osteopathic Medicine

Background

Patients with advanced dementia have distinct end-of-life needs, yet hospice care quality may be shaped not only by how the setting is managed, but also by structural and environmental conditions that affect dignity and family experience. Prior reviews suggest that patients with dementia receive unsatisfactory palliative care, while dignity-centered care depends on respect, comfort, family support, and care settings capable of meeting complex needs. Studies also suggest racial and ethnic disparities in hospice access and end-of-life utilization among people with dementia. Reviews support the need for dementia-specific palliative approaches and suggest that the care environment influences end-of-life wellbeing.

Objective

To synthesize current literature on how hospice access, environmental conditions, and system-level constraints shape dignity-centered end-of-life care in advanced dementia.

Methods

Scoping review of literature identified through PubMed using terms related to advanced dementia, hospice, palliative care, dignity, family experience, environmental design, and barriers. Priority was given to review articles, qualitative studies, and health services research examining dementia-specific end-of-life needs, environmental features, and barriers affecting hospice access or quality. Because dignity is often not directly measured in this literature, attention was given to studies using patient- or family-reported outcomes as indirect indicators of dignity, including respect, comfort, autonomy, and satisfaction with care.

Why Dementia Hospice Care Is Different

- Advanced dementia often has an unpredictable course, making prognosis and hospice timing more difficult than in many terminal illnesses.
- Communication is often limited in late-stage dementia, which can make symptom assessment, goals-of-care discussions, and advance care planning more challenging.
- Family members frequently serve as surrogate decision-makers, increasing the importance of caregiver support and clear communication from the care team.

Disparities in End-of-Life

Table 2. Unadjusted Hospice Use, Emergency Department Visits, and Hospitalizations in the Last 180 Days of Life and End-of-Life Care Preferences Among Dementia Decedents by Race and Ethnicity

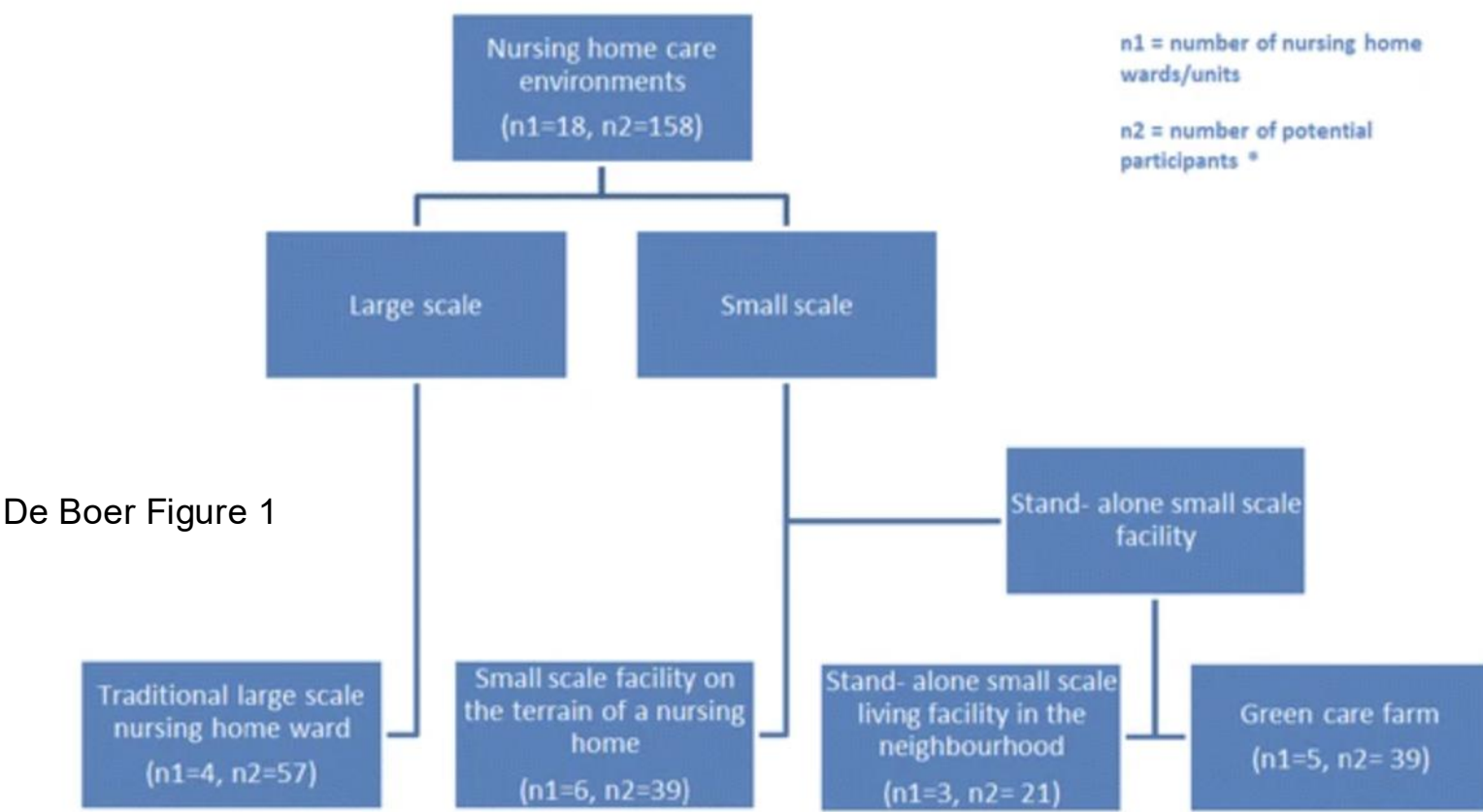
End-of-life service	Respondents, No. (%)				P value
	All (N = 5058)	Non-Hispanic White (n = 3892)	Non-Hispanic Black (n = 809)	Hispanic (n = 357)	
Hospice care					
Any hospice enrollment	2429 (48.0)	1967 (50.5)	309 (38.2)	153 (42.9)	<.001
Total hospice days, mean (SD), d ^a	49.9 (61.3)	50.4 (61.8)	50.1 (59.9)	43.5 (57.4)	.41
Hospice enrollment only during the last 7 d of life ^a	735 (30.3)	606 (30.8)	84 (27.2)	45 (29.4)	.42
Hospice enrollment only during the last 3 d of life ^a	334 (13.8)	269 (13.7)	43 (13.9)	22 (14.4)	.97
ED visits					
Any visit after hospice enrollment	269 (11.1)	191 (9.7)	56 (18.1)	22 (14.4)	<.001
Any visit	3672 (72.6)	2753 (70.7)	645 (79.7)	274 (76.8)	<.001
Total No. of outpatient visits, mean (SD) ^a	2.5 (2.1)	2.5 (2.0)	2.8 (2.2)	2.4 (2.1)	.06
Total No. of inpatient visits, mean (SD) ^a	1.8 (1.2)	1.7 (1.1)	2.2 (1.4)	1.9 (1.1)	<.001
Hospitalization					
Any hospitalization after hospice enrollment	184 (7.6)	119 (6.1)	48 (15.5)	17 (11.1)	<.001
Any hospitalization	3530 (69.8)	2630 (67.6)	625 (77.3)	275 (77.0)	<.001
Total No. of hospitalizations, mean (SD) ^a	2.1 (1.4)	2.0 (1.3)	2.4 (1.5)	2.3 (1.5)	<.001
Length of stay, mean (SD), d ^a	8.5 (7.0)	8.0 (6.6)	10.0 (8.5)	9.6 (6.6)	<.001
Advance care planning (4286 respondents)	2083 (48.6)	1871 (57.2)	146 (20.7)	66 (21.4)	NA
All care possible to prolong life (2061 respondents)	114 (5.5)	72 (3.9)	30 (20.8)	12 (18.5)	NA
Limited care (2045 respondents)	1873 (91.6)	1708 (92.8)	114 (80.9)	51 (79.7)	NA
Any treatment withheld (2001 respondents)	1576 (78.8)	1448 (80.5)	87 (62.1)	41 (66.1)	NA
Comfortable and pain free but forego extensive measures to prolong life (2041 respondents)	1886 (92.4)	1712 (93.1)	120 (87.0)	54 (83.1)	NA

Lin Figure 1

Structural Barriers to Hospice Access

- Dementia is often not recognized as a terminal illness, which can delay palliative care referral and hospice enrollment.
- Prognostic uncertainty makes it difficult for clinicians and families to identify the right time to transition from disease-focused care to comfort-focused care.
- Reimbursement and policy structures may favor crisis-driven care and hospital transfer over sustained, dementia-focused hospice support.
- Limited staff training and inconsistent communication can make goals-of-care discussions, advance care planning, and family decision-making more difficult.

Environmental Features That Support Dignity



Conclusion

Dignity in dementia hospice care should be understood as both a clinical and structural outcome. Improving end-of-life care for people with dementia may require not only better symptom management but also stronger hospice access pathways, funding that supports dementia-specific care, and environments that reduce neglect, distress, and unnecessary intervention. Future work should evaluate how hospice design, reimbursement, caregiver education, and equity-sensitive quality measures shape quality of dying with dementia.

References

Bamford C, et al. What enables good end of life care for people with dementia? BMC Geriatr. 2018;18(1):302. doi:10.1186/s12877-018-0983-0

Bosco A, et al. Caregiver experiences of hospice dementia care: a systematic review and meta-ethnography. Aging Ment Health. 2024;28(2):197-206. doi:10.1080/13607863.2023.2241027

Bosco A, et al. Experiences of hospice dementia care: a qualitative study of bereaved carers and hospice clinicians. PLoS One. 2023;18(11):e0286493. doi:10.1371/journal.pone.0286493

Cadigan RO, et al. The quality of advanced dementia care in the nursing home: the role of special care units. Med Care. 2012;50(10):856-862. doi:10.1097/MLR.0b013e318265ba2d

Chaudhury H, et al. The influence of the physical environment on residents with dementia in long-term care settings. Gerontologist. 2018;58(5):e325-e337. doi:10.1093/geront/gnw259

Connolly A, et al. End-of-life care for people with dementia from ethnic minority groups. J Am Geriatr Soc. 2012;60(2):351-360. doi:10.1111/j.1532-5415.2011.03754.x

de Boer B, et al. Living at the farm: innovative nursing home care for people with dementia. BMC Geriatr. 2015;15:144. doi:10.1186/s12877-015-0141-x

Erel M, et al. Barriers to palliative care for advanced dementia. Ann Palliat Med. 2017;6(4):365-379.

Froggatt K, et al. Namaste care intervention for people with advanced dementia in care homes. Health Technol Assess. 2020;24(6):1-140. doi:10.3310/hta24060

Gupta E, et al. Palliative care in dementia. Ann Palliat Med. 2024;13(4):791-807. doi:10.21037/apm-23-503

Harrison KL, et al. Hospice improves care quality for older adults with dementia. Health Aff. 2022;41(6):821-830. doi:10.1377/hlthaff.2021.01985

Johnson KS, et al. Racial differences in hospice revocation to pursue aggressive care. Arch Intern Med. 2008;168(2):218-224. doi:10.1001/archinternmed.2007.36

Li Q, et al. End-of-life quality of care among nursing home residents with and without dementia. J Am Med Dir Assoc. 2013;14(8):555-560. doi:10.1016/j.jamda.2013.05.008

Luth EA, et al. Associations between dementia diagnosis and end-of-life care utilization. J Am Geriatr Soc. 2022;70(10):2871-2883. doi:10.1111/jgs.17952

Sachs GA, et al. Barriers to excellent end-of-life care for patients with dementia. J Gen Intern Med. 2004;19(10):1057-1063. doi:10.1111/j.1525-1497.2004.30329.x

Sagha Zadeh R, et al. Environmental design for end-of-life care in institutional settings. J Pain Symptom Manage. 2018;55(3):1018-1034. doi:10.1016/j.jpainsymman.2017.09.011

Singh T, et al. Racial and ethnic differences in hospice use and hospitalizations among Medicare beneficiaries with dementia. JAMA Netw Open. 2022;5(6):e2215852.

Wang C, et al. Management of dementia worldwide: policy, guidelines, end-of-life care, and challenges. Biosci Trends. 2022;16(2):119-129. doi:10.5582/bst.2022.01042