

HHS Public Access

J Pain Symptom Manage. Author manuscript; available in PMC 2017 November 01.

Published in final edited form as:

Author manuscript

J Pain Symptom Manage. 2016 November ; 52(5): 663–672. doi:10.1016/j.jpainsymman.2016.05.020.

Pain Assessment, Management, and Control Among Patients 65 Years or Older Receiving Hospice Care in the U.S.

Meagan E. Cea, MA,

Department of Radiology, Weill Cornell Medical College, New York, New York, USA

M. Carrington Reid, MD,

Division of Geriatrics and Palliative Care, Department of Medicine, Weill Cornell Medical College, New York, New York, USA

Charles Inturrisi, PhD,

Department of Pharmacology, Weill Cornell Medical College, New York, New York, USA

Lisa R. Witkin, MD,

Weill Cornell Pain Medicine, Department of Anesthesiology, Weill Cornell Medical College, New York, New York, USA

Holly G. Prigerson, PhD, and

Division of Geriatrics and Palliative Care, Department of Medicine, Weill Cornell Medical College, New York, New York, USA

Yuhua Bao, PhD

Department of Healthcare Policy and Research, Weill Cornell Medical College, New York, New York, USA

Department of Psychiatry, Weill Cornell Medical College, New York, New York, USA

Abstract

Context—Knowledge is limited regarding pain assessment and management practices, as well as pain-related outcomes in hospice care.

Objectives—To generate national estimates of pain assessment and management practices and outcomes of pain control among patients 65 years or older receiving hospice care in the U.S. and identify hospice discharge and agency characteristics predicting study outcomes.

Methods—The 2007 National Home Health and Hospice Care Survey was analyzed. Multivariate logistic regressions were estimated to identify discharge and agency characteristics predicting guideline-concordant pain assessment and management practices and pain control outcomes.

Address correspondence to: Yuhua Bao, PhD, Department of Healthcare Policy and Research, Weill Cornell Medical College, 402 East 67th Street, New York, NY 10065, USA. yub2003@med.cornell.edu.

Disclosures

The authors report no other conflicts of interest.

Results—A high percentage of discharges had pain assessment at admission (97%) and before discharge (93%); use of valid pain rating scales was relatively low (69% and 54% for first and last assessments, respectively). Almost 95% of patients received pain medication, but only 42% received nonpharmacologic therapies. About 70% of patients assessed with a valid pain scale saw improvement in the level of pain or remained free of pain from admission to discharge. Non-Hispanic blacks were less likely to have pain assessments, and Hispanics were less likely to receive opioid analgesics or to have pain-free status at discharge, compared with non-Hispanic whites. Patients receiving care from for-profit (vs. nonprofit) agencies were more likely to receive pain assessment with a valid scale before discharge but less likely to experience pain control or improvement.

Conclusion—Greater use of valid pain assessment scales and nonpharmacologic therapies constitutes areas for improvement in hospice care. Targeted interventions are needed to address disparities in pain care by patient race and/or ethnicity and agency ownership status.

Keywords

Hospice; pain control; pain assessment

Introduction

Pain is a common symptom affecting people at the end of life (EOL). About two-thirds of patients with advanced cancer¹ and more than 50% of patients with end-stage chronic diseases other than cancer² experience pain. About one of three patients receiving hospice care reported uncontrolled pain at the last hospice visit before death.³ Although pain management is a priority of hospice care,⁴ available evidence indicates that pain is often inadequately managed in this setting.^{5,6} As a result, the potential benefits of hospice care to improve the quality of life when death is imminent may not be fully realized.

Pain assessment and management practices undertaken by hospice providers have direct implications for pain control among hospice patients. To date, knowledge is limited as to whether pain is systematically assessed, how it is assessed, what pain management strategies are undertaken, and the types of pain-associated outcomes achieved among U.S. patients receiving hospice care across various settings.^{6–9} The few existing studies focused on a single setting (e.g., community-based hospice⁷ or nursing homes^{6,8,9}). None examined outcomes of hospice pain management measured by changes in assessed pain from hospice admission to the time of discharge. This knowledge gap hinders the development of clinical guidelines and protocols to address suboptimal pain control at EOL in the hospice setting.

In an effort to address this gap, we used the most recent wave of the 2007 National Home Health and Hospice Care Survey (NHHCS)¹⁰ to generate national estimates of pain assessment and management practices as well as pain control outcomes among patients 65 years or older receiving hospice care in the U.S. Patients aged 65 years and older constitute a particularly important subgroup to study. They account for 83% of all hospice discharges.³ High levels of cognitive impairment, comorbidity, and polypharmacy, as well as increased sensitivity to the effects of medication, make pain management especially challenging in this

growing patient population.^{7–10} In addition, we sought to identify patient, hospice agency, and geographic factors predicting these outcomes.

Methods

Sample and Data

Our sample included hospice discharges of patients aged 65 years or older in the 2007 NHHCS, the most recent survey of Medicare-and/or Medicaid-certified home health and hospice care in the U.S.¹⁰ The survey used a stratified two-stage probability sample design. In the first stage, agencies were randomly selected based on strata defined by the type of services provided (i.e., home health, hospice, or both types of care) and metropolitan statistical areas. These agencies were required to be certified by Medicare or Medicaid, licensed by a state, and currently providing or recently provided home health or hospice services.¹⁰ In the second stage, up to 10 current home health patients, recent hospice discharges, or a combination of the two (for mixed agencies) were randomly selected from each agency. The overall unweighted response rate was 66% (weighted 55%). The 2007 NHHCS was the first survey in the series to collect medication data.

Data in the Patient Health Module of the NHHCS were collected between August 2007 and February 2008 through interviews with designated hospice staff, who completed the survey based on patient medical and medication records and hospice administrative reports. For each hospice discharge, the interviewer collected the names (brand or generic) of up to 25 medications, including all standing, routine, and as-needed medications the patient had been taking during the seven days before and on the day of discharge.³ No information on drug dosage, formulation, route, or frequency of administration was collected.

Measures

Pain Assessment—Pain assessment is measured by dichotomous indicators of whether pain was assessed at admission to hospice (first assessment) and at the last hospice visit before discharge (last assessment), and, if assessed, whether a valid rating scale was used. The use of valid pain scales enables clinicians to track changes in the presence and intensity of pain over consecutive assessments and, in turn, adjust treatment if indicated. It is thus considered an important element of evidence-based practices of pain management in hospice care.^{7,11,12} Our definition of valid pain scales was restricted to the following scales asked in NHHCS: the 0–5 or 0–10 Numeric Rating Scale,^{13–16} 0–5 or 0–10 Face Scale,^{14,17,18} Verbal Rating Scale (none, mild, moderate, or severe),¹⁶ and Face, Legs, Activity, Cry, Consolability Scale.¹⁹ The numeric, face, and verbal scales are based on patient self-report; and the Face, Legs, Activity, Cry, Consolability scale is based on observation by the assessor (usually used for patients unable to self-report because of significant sickness or cognitive impairment). To the extent that hospice providers used valid pain scales other than the aforementioned one, our results would underestimate the use of valid pain scales in hospice.

Pain Management—Dichotomous indicators of any analgesic medication (standing or PRN [as needed] orders), any nonpharmacologic method, and any pain management strategy (medication or nonpharmacologic) are derived based on responses to the NHHCS Patient

Health Module. Nonpharmacologic methods were recommended by major guidelines for cancer and palliative care to add to the benefits of analgesic use.^{11,12} The NHHCS gave examples of nonpharmacologic methods (distraction, heat and/or cold, massage and/or positioning, and music therapy) but did not collect data on the specific methods used. Using the NHHCS medication data, we also derived dichotomous indicators of use of opioid analgesics and nonopioid analgesics during the seven days before and on the day of the hospice discharge, the time frame adopted by the survey. Denominator for all pain management variables was restricted to hospice discharges with a first assessment of pain.

Pain Control Outcomes—The first measure was whether the patient had pain-free status at discharge, defined as one (zero otherwise) if the last pain assessment indicated no pain. The second measure was a composite measure of pain improvement and/or maintenance of effective pain control from the first to last assessment and was restricted to hospice discharges for which both assessments were conducted using a numeric, face, or verbal rating scale. Previous studies have established significant correlations²⁰ and developed equivalency cutpoints among these scales, enabling us to categorize pain levels into three categories indicating none, mild to moderate, or severe pain (Table 1).^{21,22} Pain improvement (vs. no improvement or deterioration) was one (zero otherwise) if the recoded pain level changed from severe to mild-moderate or none, or from mild-moderate to none, from first to last assessments for patients who received some pain management interventions during hospice, indicating a need for pain control. Because no pain cannot be improved on, maintaining a no pain status suggests effective pain management.

Hospice discharge characteristics included patient age (65–74, 75–84, and 85+), gender, race and/or ethnicity (non-Hispanic white, non-Hispanic black, Hispanic, and other), whether the patient had a primary caregiver other than the home health agency, setting of hospice care (hospice agency inpatient and/or residential facility, private home, nursing home and/or skilled nursing facility, or hospital), whether cancer was the primary diagnosis at hospice admission, cognitive status (no, mild, or serious cognitive impairment), deceased at discharge, lengths of hospice stay (7, 8–21, 22–84, and 85+ days), having a living will, and having a do-not-resuscitate (DNR) order on file. Hospice agency characteristics included ownership status (for profit vs. private not-for-profit or government agencies; not-for-profit and government agencies were grouped together in NHHCS data), whether the agency belonged to a chain, and location of the agency in a metropolitan, micropolitan, or rural and/or nonurban area.^{23,24}

Statistical Analysis

We derived nationally representative estimates of pain assessment, pain management, and pain control outcomes using sampling weights developed by NHHCS to reflect the complex sample design and nonresponse.¹⁰ We conducted a series of multivariate logistic regression analyses to identify hospice discharge and agency characteristics associated with study outcomes. The unit of analysis for all analyses was hospice discharge. All regression models included the complete set of hospice discharge and agency characteristics with the following exceptions. Cognitive impairment status was missing for 12.7% of the study sample and was

conceptually an important predictor of valid pain assessment tool use but less so for other outcomes. We therefore included it as a covariate in the analysis of valid pain scale use but not the other regression analyses. Sensitivity analysis, performed by including cognitive impairment status in the models for pain management and pain control, indicated that cognitive impairment was not a significant predictor of either. The models for pain control outcomes included two indicators of pain management strategies, opioid analgesic use and nonpharmacologic method to control pain. The model for no pain at last assessment controlled for the presence and/or the absence of pain at first assessment. Robust standard errors were derived by accounting for clustering at the hospice agency level. All analyses were conducted using STATA, version 13.0 (STATA Corp., College Station, TX).

Results

Table 2 presents the unweighted sample sizes and weighted descriptive statistics of hospice discharge and hospice agency characteristics. Table 3 presents weighted and nationally representative estimates of pain assessment, pain management, and pain control outcomes. An estimated 97.1% of hospice discharges had a pain assessment at admission, 68.9% of which were conducted with a valid pain scale. A lower percentage had a last assessment (92.8%), of which only 53.8% were conducted with a valid pain scale. Of all hospice discharges with a first pain assessment, close to 96% received pain management interventions, including standing or PRN medication (8.8% had standing only, 29.3% had PRN only, and 56.4% had both standing and PRN), and nonpharmacologic approaches (42.0%). Opioid analgesics were administered for 85.2% and nonopioid analgesics for 58.4% of all hospice discharges during the seven days before or on the day of discharge. A substantial majority of patients with both first and last assessments had no reported pain at first (63.7%) and last assessment (71.0%), respectively. Of all patients assessed with numeric, face, or verbal scales at both assessments and with a need for pain control, 70.1% had an improvement in the level of their pain or maintained effective pain control from admission to discharge.

Pain Assessment

As shown in Table 4, being a non-Hispanic black (vs. non-Hispanic white) was associated with a lower likelihood of receiving a first assessment (adjusted odds ratio [AOR] = 0.26, P < 0.05) or a last assessment (AOR = 0.47, P < 0.05). In addition, having hospice lengths of stay greater than seven days was associated with an AOR of >4 (P < 0.01) for last assessment compared with lengths of stay of seven days or less. Conditional on having received a first or last assessment, the following discharge characteristics were associated with a higher or lower likelihood of valid pain scale use with P-value < 0.01: age 85 or older (vs. 65–74) (AOR = 0.66 at first and 0.75 at last assessments), receiving hospice at home (vs. agency facility) (AOR = 1.55 at first and 1.33 at last assessments), cancer as primary diagnosis (AOR = 1.62 at first assessment), serious (vs. no) cognitive impairment (AOR = 0.31 at first and 0.51 at last assessments), lengths of stay greater than seven days (AOR = 0.58 at first and 0.33 at last assessment). In addition, receiving hospice care from a for-profit agency

(vs. not-for-profit or government agency) was associated with an AOR of 1.49 (P < 0.05) of valid pain scale use at last assessment.

Pain Management

The following discharge characteristics predicted a lower likelihood of receiving opioid analgesics with P < 0.05 (Table 5): 85 years or older (vs. 65–74; AOR = 0.70), Hispanic (vs. non-Hispanic white; AOR = 0.62), and having lengths of stay of 8–21 days (vs. seven days and fewer; AOR = 0.68). Cancer as the primary hospice diagnosis (AOR = 3.39), deceased at discharge (AOR = 4.78), and having a DNR order (AOR = 1.40) significantly predicted a greater likelihood of receiving opioids (P < 0.01). Older age (85 or older vs. 65–74) and receiving hospice care at a place other than a hospice agency facility significantly predicted a lower likelihood of receiving nonpharmacologic pain management strategies. Deceased at discharge, having lengths of stay greater than seven days, having a living will, and having a DNR order each predicted a greater likelihood of receiving nonpharmacologic pain management interventions.

Pain Control

As shown in Table 6, Hispanic ethnicity (AOR = 0.65), a primary diagnosis of cancer (AOR = 0.71), and use of opioid analgesics (AOR = 0.65) predicted a lower likelihood of having no pain at last assessment (P < 0.05). Having no pain at first assessment strongly predicted no pain at last assessment (AOR = 3.17, P < 0.01). Having a primary diagnosis of cancer (AOR = 0.63) and use of opioid analgesics (AOR = 0.54) predicted a lower likelihood of pain improvement or maintenance of effective pain control from first to last assessment. On the other hand, having lengths of hospice stay of 8–21 days (compared with seven days or less, AOR = 1.54) and having a DNR directive predicted a greater likelihood of pain improvement or maintenance of effective pain control. For-profit status of the agency was associated with a lower likelihood of both pain control outcomes (AOR = 0.76 for no pain at last assessment and AOR = 0.67 for pain improvement).

Discussion

Our analysis of the 2007 NHHCS provides the first known nationwide estimates of pain assessment, management practices, and control outcomes, which could be used as benchmarks for hospice quality improvement and future studies in this area. We found that, nation wide, hospice patients 65 years or older received a high level of pain assessment but a relatively low level of use of valid pain scales. They had a very high level of pain medication use and, in particular, opioid analgesic use, but a much lower level of nonpharmacologic strategies, to manage their pain. Among patients assessed at both admission and discharge, most (71%) had no reported pain at hospice discharge, and a similar proportion saw improvement in the level of their pain or maintained effective pain control. Our analysis also revealed disparities, by patient characteristics or agency types, in terms of pain assessment, management, and control outcomes. In particular, non-Hispanic blacks were less likely to have their pain assessed and Hispanics were less likely to have received opioid analgesics or to have pain-free status at discharge, compared with non-Hispanic white patients. Although patients receiving care from for-profit agencies were more likely to be assessed for pain with

a valid pain scale at discharge, they were less likely to have pain-free status at discharge or to experience pain improvement or maintain effective pain control compared with patients treated by nonprofit or government agencies.

We found that less than three of four patients at first assessment and less than three of five patients at last assessment had their pain assessed with a valid pain scale. The physical and cognitive impairments typically experienced by patients at EOL may explain the low use of valid pain scales to some extent.²⁵ Valid pain scales for patients with cognitive impairments or otherwise not able to self-report pain (e.g., Pain Assessment in Advanced Dementia [PAINAD] and Pain Assessment Checklist for Seniors with Limited Ability to Communicate [PACSLAC]) do exist^{26–28} but were not asked in NHHCS. It is thus possible that this study underestimated the rate of valid pain scale use. In any case, the current low level of valid pain scale use represents a quality gap that is likely amenable to future intervention efforts including education of hospice clinicians about recommended tools for pain assessment and implementation and dissemination efforts.²⁹

Our results indicated that slightly more than 40% of older hospice patients used some nonpharmacologic strategies to manage their pain, compared with almost 95% who received pain medication. Availability and use of nonpharmacologic approaches was lower in hospice settings other than hospice agency facilities. This is at odds with cancer pain management guidelines¹¹ and best practices for palliative care¹² recommending the use of nonpharmacologic therapies in conjunction with pain medications and reveals an important gap in the quality of pain management. This gap is of particular concern for patients with advanced age (shown to be less likely to receive nonpharmacologic therapies than younger patients), for whom opioid analgesics are not always safe and could lead to detrimental side effects and/or decreased quality of life at EOL.³⁰ Future efforts in hospice quality improvement and performance evaluations should consider use of nonpharmacologic strategies as an important area.

Our findings suggested that patients with a DNR order were more likely to have received opioid analgesics and nonpharmacologic therapies as well as achieved better pain control outcomes. This could reflect differences in the culture of hospice agencies. For example, agencies with a protocol to encourage DNR and other advanced directives by their patients may also be more likely to provide both opioid analgesics and nonpharmacologic therapies. It could also reflect differences in patient preferences in the sense that patients with a preference for less-intensive EOL care value pain control and seek out hospice agencies that provide multiple strategies of pain control. Although our data do not allow us to examine the underlying reasons, our finding is consistent with findings of previous studies that advance care planning was associated with better quality of life at the EOL.³¹

Related, we found that patients with longer lengths of stay in hospice, compared with onethird of the population that stayed for seven or fewer days, received more adequate pain assessment, more non-pharmacologic strategies, and achieved better pain improvement. This confirms findings of previous studies that timely admission to hospice (rather than delaying to the final days) improves EOL outcomes for patients.^{32,33}

Consistent with the existing literature, our analysis found substantially lower rates of pain assessments among non-Hispanic blacks, substantially lower rates of opioid analgesic use near EOL,^{34,35} and worse pain control outcomes^{36,37} among Hispanics, compared with non-Hispanic whites. Previous studies have suggested that factors at the patient, provider, and system levels contribute to these differences.^{34,37} The racial and/or ethnic differences we observed are likely a result of both within-agency differences—that white and minority patients within the same agency received different pain management—and between-agency differences—that hospice agencies disproportionately serving minority patients were less likely to adequately assess pain or offer opioid analgesics to patients (because of perceived low demand, concerns for diversion of opioids, or other reasons). As found in previous studies that pharmacies in predominantly nonwhite neighborhoods in New York City stocked inadequate supply of opioids,³⁸ between-hospice agency differences in pain management reflect systematic factors and may be amenable to educational and quality improvement interventions targeting agencies serving a disproportionately large number of minority patients.

Our analysis also revealed concerning differences by agency ownership status in pain assessment, management, and pain control outcomes. Although for-profit status of agency was associated with a higher rate of use of valid pain scales, patients receiving care from for-profit agencies experienced worse pain outcomes compared with those treated by not-for-profit or government agencies. Patients cared for by for-profit agencies had longer lengths of stay (indicating better prognosis),^{39,40} which may partly explain the greater use of valid pain scales at these agencies. However, given the more favorable case mix of patients, the lower rates of pain-free status at discharge and of pain improvement found at for-profit agencies strongly suggest a lower quality of pain management at these agencies. This is consistent with the lower or comparable quality of home health care associated with for-profit status of hospice agencies.⁴²

Our study has several limitations. Information on pain assessment and pain management strategies were based on hospice clinical records and not direct observation by a third party and therefore susceptible to inaccuracies in documentation. The pain control outcomes we measured were based on pain assessments conducted in the hospice setting. Possible inaccuracy in pain assessments may bias our estimates; lack of assessments because of patient factors (e.g., cognitive impairment) or provider factors (e.g., systematically lower use of valid pain scales at some agencies) would exclude a selected sample from our analysis of pain control outcomes, making our findings potentially nongeneralizable to the population of hospice patients 65 years or older. In addition, we were not able to assess pain outcomes that are more patient centered than measured in this study because the NHHCS did not provide data on acceptable levels of pain or preferred pain management strategies by patients. Finally, although the most recently available national survey, the 2007 NHHCS is almost a decade old. Current practices and outcomes of pain management in hospice are likely to have improved as a result of increased use of hospice care and increased awareness of a need to improve quality. Although our data provide important benchmarks, the findings need to be re-examined when more recent data become available.

Conclusions

Our analysis of the 2007 NHHCS revealed several important gaps in the practices and quality of pain management for patients 65 years or older receiving hospice care. Patients of racial and/or ethnic minorities (compared with whites) and patients cared for by for-profit agencies (compared with not-for-profit agencies) fared worse in pain management and/or pain control outcomes. Hospice quality improvement efforts may consider the use of valid pain scales and of nonpharmacologic pain management therapies as performance measures. Targeted interventions are needed to address disparities in pain care by race and/or ethnicity and by agency ownership status.

Acknowledgments

This study is funded by a pilot grant from the Translational Institute on Pain in Later Life at Cornell and Columbia Universities (P30AG022845). Drs. Bao and Prigerson are also funded by a grant from the National Cancer Institute (CA195530).

Dr. Inturrisi has an equity (stock) ownership in Relmada Therapeutics, a company developing new analgesics.

References

- 1. Institute of Medicine. Relieving pain in America: A blueprint for transforming prevention, care, education, and research. Washington, DC: The National Academies Press; 2011.
- Solano JP, Gomes B, Higginson IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. J Pain Symptom Manage. 2006; 31:58–69. [PubMed: 16442483]
- Center for Disease Control and Prevention, National Center for Health Statistics. Chartbook, special feature on death and dying. Hyattsville, MD: National Center for Health Statistics; 2010. Health, United States 2010.
- 4. Higginson I, Evans C. What is the evidence that palliative care teams improve outcomes for cancer patients and their families? Cancer J. 2010; 16:423–435. [PubMed: 20890138]
- Teno J, Shu J, Casarett D, et al. Timing of referral to hospice and quality of care: length of stay and bereaved family members' perceptions of the timing of hospice referral. J Pain Symptom Manage. 2007; 34:120–125. [PubMed: 17583469]
- Hanlon JT, Perera S, Sevick MA, Rodriguez KL, Jaffe EJ. Pain and its treatment in older nursing home hospice/palliative care residents. J Am Med Dir Assoc. 2010; 11:579–583. [PubMed: 20889094]
- Herr K, Titler M, Fine P, et al. Assessing and treating pain in hospices: current state of evidencebased practices. J Pain Symptom Manage. 2010; 39:803–819. [PubMed: 20471542]
- 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]
- Miller SC, Mor V, Teno J. Hospice enrollment and pain assessment and management in nursing homes. J Pain Symptom Manage. 2003; 26:791–799. [PubMed: 12967728]
- 10. National Center for Health Statistics. National Home And Hospice Care Survey And National Home Health Aide Survey. Hyattsville, MD: National Center for Health Statistics; 2007.
- 11. Miaskowski, C., Cleary, J., Burney, R., et al. Guideline for the management of cancer pain in adults and children. Glen-view, IL: American Pain Society; 2004.
- The National Consensus Project for Quality Palliative Care. Constance Dahlin. 3rd. National Consensus Projects for Quality Palliative Care; 2013. Clinical Practice Guidelines for Quality Palliative Care. Available at http://www.nationalconsensusproject.org/ NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf

- Costello P, Wiseman J, Douglas I, Batten B, Bennett M. Assessing hospice inpatients with pain using numerical rating scales. Palliat Med. 2001; 15:257–258. [PubMed: 11407198]
- Ware LJ, Epps CD, Herr K, Packard A. Evaluation of the revised Faces Pain Scale, Verbal Descriptor Scale, Numeric Rating Scale, and Iowa Pain Thermometer in older minority adults. Pain Manag Nurs. 2006; 7:117–125. [PubMed: 16931417]
- Carpenter JS, Brockopp D. Comparison of patients' ratings and examination of nurses' responses to pain intensity rating scales. Cancer Nurs. 1995; 18:292–298. [PubMed: 7664256]
- Williamson A, Hoggart B. Pain: a review of three commonly used pain rating scales. J Clin Nurs. 2005; 14:798–804. [PubMed: 16000093]
- Hicks CL, von Baeyer CL, Spafford PA, van Korlaar I, Goodenough B. The Faces Pain Scale revised: toward a common metric in pediatric pain measurement. Pain. 2001; 93:173–183. [PubMed: 11427329]
- 18. McCaffery M. Choosing a faces pain scale. Nursing. 2002; 32:68.
- Voepel-Lewis T, Zanotti J, Dammeyer JA, Merkel S. Reliability and validity of the Face, Legs, Activity, Cry, Consolability Behavioral Tool in assessing acute pain in critically ill patients. Am J Crit Care. 2010; 19:55–61. [PubMed: 20045849]
- Closs SJ, Barr B, Briggs M, Cash K, Seers K. A comparison of five pain assessment scales for nursing home residents with varying degrees of cognitive impairment. J Pain Symptom Manage. 2004; 27:196–205. [PubMed: 15010098]
- Serlin RC, Mendoza TR, Nakamura Y, Edwards KR, Cleeland CS. When is cancer pain mild, moderate or severe—grading pain severity by its interference with function. Pain. 1995; 61:277– 284. [PubMed: 7659438]
- Jones KR, Vojir CP, Hutt E, Fink R. Determining mild, moderate, and severe pain equivalency across pain-intensity tools in nursing home residents. J Rehabil Res Dev. 2007; 44:305–314. [PubMed: 17551881]
- 23. US Census Bureau. Metropolitan and micropolitan. Available at: http://www.census.gov/ population/metro/. Accessed December 1, 2015
- 24. US Census Bureau. Urban and rural classification. Available at: https://www.census.gov/geo/ reference/urban-rural.html. Accessed December 1, 2015
- 25. Radbruch L, Sabatowski R, Loick G, et al. Cognitive impairment and its influence on pain and symptom assessment in a palliative care unit: development of a Minimal Documentation System. Palliat Med. 2000; 14:266–276. [PubMed: 10974978]
- Herr K, Bursch H, Ersek M, Miller LL, Swafford K. Use of pain-behavioral assessment tools in the nursing home: expert consensus recommendations for practice. J Gerontol Nurs. 2010; 36:18–29. quiz 30–31.
- Herr K, Coyne PJ, McCaffery M, Manworren R, Merkel S. Pain assessment in the patient unable to self-report: position statement with clinical practice recommendations. Pain Manag Nurs. 2011; 12:230–250. [PubMed: 22117755]
- Lichtner V, Dowding D, Esterhuizen P, et al. Pain assessment for people with dementia: a systematic review of systematic reviews of pain assessment tools. BMC Geriatr. 2014; 14:138. [PubMed: 25519741]
- Horner JK, Hanson LC, Wood D, Silver AG, Reynolds KS. Using quality improvement to address pain management practices in nursing homes. J Pain Symptom Manage. 2005; 30:271–277. [PubMed: 16183011]
- Dy SM. Patient safety and end-of-life care: common issues, perspectives, and strategies for improving care. Am J Hosp Palliat Care. 2016; 33:791–796. [PubMed: 25877945]
- Garrido MM, Balboni TA, Maciejewski PK, Bao Y, Prigerson HG. Quality of life and cost of care at the end of life: the role of advance directives. J Pain Symptom Manage. 2015; 49:828–835. [PubMed: 25498855]
- Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. JAMA. 2008; 300:1665– 1673. [PubMed: 18840840]

- Mack JW, Weeks JC, Wright AA, Block SD, Prigerson HG. End-of-life discussions, goal attainment, and distress at the end of life: predictors and outcomes of receipt of care consistent with preferences. J Clin Oncol. 2010; 28:1203–1208. [PubMed: 20124172]
- Anderson KO, Green CR, Payne R. Racial and ethnic disparities in pain: causes and consequences of unequal care. J Pain. 2009; 10:1187–1204. [PubMed: 19944378]
- 35. Bailey FA, Williams BR, Goode PS, et al. Opioid pain medication orders and administration in the last days of life. J Pain Symptom Manage. 2012; 44:681–691. [PubMed: 22765968]
- Laguna J, Goldstein R, Braun W, Enguidanos S. Racial and ethnic variation in pain following inpatient palliative care consultations. J Am Geriatr Soc. 2014; 62:546–552. [PubMed: 24575714]
- Shavers VL, Bakos A, Sheppard VB. Race, ethnicity, and pain among the U.S. adult population. J Health Care Poor Underserved. 2010; 21:177–220. [PubMed: 20173263]
- Morrison RS, Wallenstein S, Natale DK, Senzel RS, Huang LL. "We don't carry that"—failure of pharmacies in predominantly nonwhite neighborhoods to stock opioid analgesics. N Engl J Med. 2000; 342:1023–1026. [PubMed: 10749965]
- 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; 305:472–479. [PubMed: 21285424]
- 40. Lorenz KA, Ettner SL, Rosenfeld KE, et al. Cash and compassion: profit status and the delivery of hospice services. J Palliat Med. 2002; 5:507–514. [PubMed: 12243675]
- 41. Cabin W, Himmelstein DU, Siman ML, Woolhandler S. For-profit medicare home health agencies' costs appear higher and quality appears lower compared to nonprofit agencies. Health Aff (Millwood). 2014; 33:1460–1465. [PubMed: 25092849]
- Carlson MD, Gallo WT, Bradley EH. Ownership status and patterns of care in hospice: results from the National Home and Hospice Care Survey. Med Care. 2004; 42:432–438. [PubMed: 15083103]

Cutpoints Used to Recode Verbal, Numeric, and Face Pain Rating Scales to a Three-Category Indicator of Pain Levels

Pain Rating Scale	Pain Level Cutpoints		
Verbal Rating Scale	None	Mild-Moderate	Severe
0-5 Numeric Rating Scale	0	1–3	4–5
0-5 Face Scale	0	1–3	4–5
0-10 Numeric Rating Scale	0	1–6	7–10
0-10 Face Scale	0	1–6	7–10

Descriptive Statistics of Hospice Discharge and Hospice Agency Characteristics of Study Sample

Variables	Ν	Weighted %
Age		
65–74	801	18.6
75–84	1465	35.5
85 or older	1652	46.0
Gender		
Male	1682	43.2
Female	2236	56.8
Race/ethnicity		
Non-Hispanic white	3433	84.1
Non-Hispanic black	316	11.1
Hispanic	112	3.3
Other race/ethnicity	57	1.5
Having a primary caregiver outside agency		
Yes	3571	90.7
No	318	9.3
Place of hospice care		
Agency inpatient/residential facility	460	14.4
Private home or apartment	2197	51.2
Nursing home/skilled nursing facility	913	24.5
Hospital	328	9.9
Cancer as primary diagnosis at hospice admission		
Yes	1491	36.4
No	2427	63.6
Cognitive impairment		
No	1004	29.6
Mild	1098	28.1
Serious	1318	42.4
Deceased at discharge		
Yes	3216	84.5
No	699	15.5
Lengths of stay (days)		
0–7	1266	35.0
8–21	780	19.3
22-84	938	23.5
85+	934	22.2
Having any advanced directive		
Yes	3495	91.6
No	382	8.4
Having a living will		

Having a living will

Variables	N	Weighted %
Yes	1198	27.1
No	2679	72.9
Having a DNR order		
Yes	3164	83.5
No	713	16.6
Hospice agency ownership		
For-profit	914	31.5
Private not-for-profit agencies/government agencies	3004	68.5
Agency is part of chain		
Yes	741	27.1
No	3177	72.9
Agency location ^a		
Metropolitan	1427	87.3
Micropolitan	1454	9.0
Rural/nonurban	1037	3.7
Total number of hospice agencies	665	100.0
Total number of hospice discharges	3918	100.0

DNR = do not resuscitate.

 $^a\!\mathrm{Metropolitan},$ micropolitan, and rural are based on Census Bureau definition.

Nationally Representative Estimates of Pain Assessment, Management, and Pain Control Outcomes Among Older Patients Receiving Hospice Care

Variables	Unweighted N (Numerator/Denominator)	Weighted %
Pain assessment		
First assessment of pain conducted ^a	3826/3918	97.1
Valid pain scale used at first assessment ^b	2766/3826	68.9
Last assessment of pain conducted ^a	3659/3918	92.8
Valid pain scale used at last assessment $^{\mathcal{C}}$	2018/3659	53.8
Pain management		
Standing order for pain medication only b,d	301/3818 ^e	8.8
PRN (as needed) order for pain medication only bd	1096/3818 ^e	29.3
Standing order and PRN order for pain medication bd	2218/3818 ^e	56.4
Any nonpharmacologic strategy to manage pain bd	1720/3818 ^e	42.0
Use of opioid analgesics $b f$	3207/3826	85.2
Use of nonopioid analgesics $b f$	2165/3826	58.4
Pain control outcomes		
No reported pain at first assessment ^g	1777/3026	63.7
No reported pain at last assessment \mathcal{S}	2126/3026	71.0
Pain improvement/maintenance of effective pain control h	1068/1520	70.1

^aHospice discharges of patients 65 years or older.

^bHospice discharges of patients 65 years or older with first assessment of pain conducted.

^CHospice discharges of patients 65 years or older with last assessment of pain conducted.

 d_{Based} on responses to the National Home Health and Hospice Care Survey Patient Health Module by designated hospice staff.

 e The denominator for pain management strategies based on the questionnaire (3818) is lower than the total number of discharges with a first assessment (3826) because of missing responses to these questions.

fBased on medication data collected from hospice medical records reflecting medications taken during the last eight days before hospice discharge.

^gHospice discharges of patients 65 years or older with both first and last assessments.

^hHospice discharges of patients 65 years or older for which pain assessment tools used for both first and last assessments were one of the following: 0–10 numeric, 0–10 face, 0–5 numeric, 0–5 face and verbal categories containing none, mild, moderate, and severe. Patients with no pain at first assessment were included only if they received some pain management during their hospice care.

AORs Associated With Hospice Discharge and Agency Characteristics Predicting Pain Assessment

	First Pain Assessment Conducted ^a	Valid Pain Tool Used at First Assessment ^b	Last Pain Assessment Conducted ^a	Valid Pain Tool Used _at Last Assessment ^c
Variables	(n = 3873)	(n = 3364)	(n = 3873)	(n = 3244)
Age (ref.: 65-74), years				
75–84	1.00 (0.49–2.05)	0.98 (0.76–1.27)	0.92 (0.62–1.37)	0.94 (0.77-1.15)
85 or older	0.89 (0.44–1.81)	$0.66^d (0.51 - 0.86)$	1.01 (0.67–1.51)	$0.75^d(0.60-0.93)$
Female (vs. male)	1.09 (0.65–1.84)	0.88 (0.73-1.06)	0.95 (0.72–1.27)	0.94 (0.80–1.10)
Race (ref.: non-Hispanic white)				
Non-Hispanic black	$0.26^d (0.11 - 0.65)$	0.95 (0.66–1.39)	0.47^d (0.27–0.83)	0.85 (0.59–1.23)
Hispanic	1.19 (0.16-8.78)	1.18 (0.60–2.31)	1.94 (0.62–6.15)	1.07 (0.65–1.77)
Other race/ethnicity	0.58 (0.07-4.66)	0.59 (0.31–1.14)	1.14 (0.27–4.90)	0.91 (0.50-1.65)
Place of hospice care (ref.: agency facility)				
Private home	1.87 (0.85–4.12)	$1.55^d(1.14-2.11)$	0.87 (0.49–1.56)	1.33 ^e (1.00–1.75)
Nursing home/skilled nursing facility	2.21 (0.85-5.75)	1.15 (0.83–1.59)	0.78 (0.43–1.44)	1.15 (0.85–1.56)
Hospital	0.81 (0.34–1.95)	1.11 (0.71–1.76)	$0.43^d (0.24-0.77)$	1.25 (0.80–1.95)
Cancer as primary diagnosis at admission	1.08 (0.61–1.90)	1.62 ^d (1.29–2.02)	1.02 (0.75–1.40)	0.97 (0.82–1.16)
Cognitive status (ref .: no impairment)				
Mild impairment		0.93 (0.70-1.23)		0.89 (0.72–1.10)
Serious impairment		$0.31^d(0.24-0.41)$		0.51 ^d (0.40–0.64)
Deceased	1.14 (0.48–2.70)	0.58 ^d (0.44–0.76)	0.91 (0.48–1.71)	0.33 ^d (0.26–0.43)
Lengths of stay (ref.: 0-7 days)				
8–21 days	1.29 (0.64–2.61)	1.44 ^d (1.12–1.84)	4.19^d (2.62–6.68)	0.94 (0.76–1.16)
22-84 days	1.29 (0.60–2.77)	1.69 ^d (1.31–2.19)	$4.56^{d}(2.74-7.57)$	1.11 (0.90–1.37)
85+ days	1.44 (0.61–3.39)	1.56 ^d (1.23–1.97)	4.17 ^d (2.34–7.44)	1.06 (0.85-1.31)
Having a living will	1.39 (0.76–2.55)	1.09 (0.88–1.34)	1.01 (0.73–1.39)	0.96 (0.79–1.16)
Having a DNR directive	1.91 (0.93-3.92)	1.04 (0.77–1.40)	1.17 (0.76–1.80)	0.99 (0.76–1.28)
Agency ownership (ref.: not-for-profit agencies/government agencies)				
For profit	1.59 (0.44–5.74)	1.29 (0.87–1.91)	1.76 (0.74–4.16)	1.49 ^e (1.01–2.19)
Agency is part of chain	2.26 (0.77-6.69)	1.20 (0.80–1.82)	1.23 (0.65–2.33)	1.08 (0.73–1.60)
Agency location (ref.: metropolitan)				
Micropolitan	0.69 (0.30–1.60)	1.36 (0.99–1.87)	0.69 (0.43–1.09)	1.35 (0.98–1.84)
Rural/nonurban	0.54 (0.23-1.25)	1.13 (0.81–1.59)	0.81 (0.51-1.30)	0.97 (0.69–1.35)

AORs = adjusted odds ratios; ref. = reference; DNR do not resuscitate.

^aSample restriction: Hospice discharges of patients 65 years or older.

^bSample restriction: Hospice discharges of patients 65 years or older with first assessment of pain conducted.

^CSample restriction: Hospice discharges of patients 65 years or older with last assessment of pain conducted.

 $^{d}P < 0.01.$

 $e_{P<0.05.}$

AORs Associated With Hospice Discharge and Agency Characteristics Predicting Pain Management

	Use of Opioid Analgesics ^a	Use of Nonpharmacologic Strategy ^a
Variables	(<i>n</i> = 3816)	(<i>n</i> = 3809)
Age (ref.: 65–74)		
75–84	0.89 (0.66–1.21)	0.83 (0.69–1.00)
85 or older	$0.70^{b}(0.53-0.93)$	$0.74^{\mathcal{C}}(0.61-0.89)$
Female (vs. male)	1.06 (0.87–1.29)	1.02 (0.89–1.18)
Race (ref.: non-Hispanic white)		
Non-Hispanic black	0.82 (0.59–1.14)	0.80 (0.55–1.18)
Hispanic	$0.62^{b}(0.40-0.97)$	1.18 (0.72–1.94)
Other race/ethnicity	0.96 (0.48–1.92)	0.97 (0.51–1.83)
Place of hospice care (ref.: agency facility)		
Private home	1.08 (0.80–1.45)	$0.62^{\mathcal{C}}(0.47-0.81)$
Nursing home/skilled nursing facility	1.02 (0.73–1.42)	0.71 ^b (0.53–0.96)
Hospital	1.34 (0.82–2.18)	0.61 ^b (0.42–0.89)
Cancer as primary diagnosis at admission	3.39 ^C (2.62–4.40)	1.12 (0.96–1.31)
Deceased	4.78 ^C (3.84–5.93)	1.87 ^C (1.49–2.33)
Lengths of stay (ref.: 0-7 days)		
8–21 days	$0.68^{\mathcal{C}}(0.52-0.90)$	$1.38^{\mathcal{C}}(1.14-1.68)$
22-84 days	0.80 (0.61–1.07)	1.35 ^c (1.12–1.63)
85+ days	0.85 (0.65–1.12)	$1.29^{b}(1.05-1.60)$
Having a living will	1.02 (0.82–1.26)	1.47 ^C (1.22–1.78)
Having a DNR directive	1.40 ^C (1.10–1.78)	1.41 ^C (1.10–1.82)
Agency ownership (ref.: not-for-profit agencies/government agencies)		
For profit	0.83 (0.62–1.10)	0.99 (0.68–1.45)
Agency is part of chain	1.04 (0.75–1.44)	0.91 (0.61–1.37)
Micropolitan	0.85 (0.66–1.10)	1.10 (0.80–1.51)
Rural/nonurban	0.99 (0.74–1.33)	1.30 (0.93–1.82)

AORs = adjusted odds ratios; ref. = reference; DNR = do not resuscitate.

^aSample restriction: Hospice discharges of patients 65 years or older with first assessment of pain conducted.

 $^{b}P < 0.05.$

 $C_{P < 0.01.}$

AORs Associated With Hospice Discharge and Agency Characteristics Predicting Pain Control Outcome

	No Reported Pain at Last Assessment ^a	Pain Improvement/Maintenance of Effective Pain Control ^b
Variables	(<i>n</i> = 3019)	(n = 1517)
Age (ref.: 65–74)		
75–84	0.91 (0.73–1.13)	0.89 (0.67–1.19)
85 or older	0.91 (0.71–1.15)	0.83 (0.59–1.15)
Female (vs. male)	1.17 (0.98–1.40)	1.04 (0.82–1.33)
Race (ref.: non-Hispanic white)		
Non-Hispanic black	0.82 (0.57–1.18)	0.63 (0.38–1.02)
Hispanic	0.65 ^c (0.42–0.99)	0.63 (0.33-1.20)
Other race/ethnicity	0.72 (0.37–1.42)	0.85 (0.31-2.34)
Place of hospice care (ref.: agency facility)		
Private home	0.86 (0.64–1.14)	0.75 (0.48–1.17)
Nursing home/skilled nursing facility	0.99 (0.73–1.35)	0.95 (0.58–1.57)
Hospital	1.08 (0.71–1.65)	0.99 (0.51–1.92)
Cancer as primary diagnosis at admission	0.71 ^d (0.58–0.86)	0.63 ^d (0.48–0.82)
Deceased	1.07 (0.84–1.38)	1.13 (0.84–1.52)
Lengths of stay (ref.: 0-7 days)		
8–21 days	1.02 (0.80–1.28)	1.54 ^C (1.09–2.17)
22–84 days	0.99 (0.79–1.23)	1.22 (0.90–1.66)
85+ days	1.00 (0.78–1.28)	1.37 (0.96–1.96)
Having a living will	0.93 (0.76–1.13)	1.10 (0.83–1.44)
Having a DNR directive	1.20 (0.97–1.49)	1.39 ^C (1.04–1.84)
For profit	$0.76^{\mathcal{C}}(0.58-1.00)$	$0.67^{\mathcal{C}}(0.48-0.95)$
Agency is part of chain	0.87 (0.65–1.18)	1.16 (0.79–1.70)
Agency location (ref.: metropolitan)		
Micropolitan	0.93 (0.74–1.17)	1.03 (0.74–1.43)
Rural/nonurban	1.01 (0.80–1.28)	0.91 (0.65–1.28)
Use of opioid analgesics	$0.65^d (0.49-0.85)$	$0.54^d(0.38-0.77)$
Use of any nonpharmacologic strategy	1.04 (0.86–1.26)	1.05 (0.81–1.37)
No pain at first assessment	3.17 ^d (2.63–3.83)	

AORs = adjusted odds ratios; ref. = reference; DNR = do not resuscitate.

^aSample restriction: Hospice discharges of patients 65 years or older with both first and last assessments.

 b Sample restriction: Hospice discharges of patients 65 years or older for which pain assessment tools used for both first and last assessments were one of the following: 0–10 numeric, 0–10 face, 0–5 numeric, and 0–5 face and verbal categories containing none, mild, moderate, and severe. Also, includes patients with no pain at first assessment only if they received some pain management during their hospice care.

 $^{C}P < 0.05.$

 $^{d}P < 0.01.$

Author Manuscript