Abstract

Context. Pain management is suboptimal in nursing homes.

Objectives. To estimate the extent to which receipt of hospice in nursing homes (NHs) increases the receipt of pain management for residents with cancer at the end of life.

Methods. Study participants included Medicare beneficiaries with cancer who were NH residents in the last 90 days of life in 2011–2012 (n = 78,160). Residents in pain on hospice were matched to like residents without hospice by facility, type of pain assessment (self-report/staff assessment), and weeks until death (9064 matched strata, 16,968 unique residents). Minimum Data Set 3.0 provided information on residents’ pain prevalence and receipt of pain management (scheduled analgesics, as needed [pro re nata (PRN)] medication, nonpharmacologic interventions). We developed conditional logistic models to estimate the association between hospice use and pain management, stratified by self-reported and staff-assessed pain.

Results. We found that pain prevalence was higher in residents using hospice versus those without hospice (e.g., residents who self-reported pain: hospice: 59.9%, 95% CIs = 59.3–60.5%; nonhospice: 50.0%, 95% CI = 49.4–50.6%). In matched analyses, untreated pain was uncommon (self-reported pain: 2.9% and 5.6% in hospice users and nonusers, respectively). Hospice use was associated with receipt of scheduled analgesics (self-reported: adjusted odds ratio = 1.85, 95% CI = 1.73–1.97) and PRN medication (self-reported: adjusted odds ratio = 1.31, 95% CI = 1.20–1.43). Pain prevalence and the association between hospice and pain management were similar in residents with staff-assessed pain.

Conclusion. Untreated pain at the end of life among residents with cancer in NHs is unusual. Hospice is associated with increased pain management among those with documented pain.

Key Words
Nursing home, hospice, cancer, pain, pain management

Introduction

In 2009, one of six Medicare decedents with cancer died in a nursing home (NH).1 The majority experienced pain,2 the most common symptom of cancer in older adults.3–4 Cancer pain can be effectively treated in most patients using clinical guidelines,5–8 and the alleviation of pain is a primary goal of dying residents and their families.9–11 Despite this, the prevalence of untreated and undertreated cancer pain in NHs has been reported to be unacceptably high.12,13

Barriers to effective pain management in NHs include limited physician visits, inadequate staffing, and an organizational culture that prioritizes improving and maintaining resident function over providing palliative care.14–16 Dying NH residents often only have access to palliative care through enrollment into hospice care,17,18 available to Medicare beneficiaries with a life expectancy less than or equal to six months and who agree to forgo curative treatment.19 Hospice providers improve pain management through their expertise in pain assessment and

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Accepted for publication: October 24, 2016.

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analgesic use. Although NH residents who experience pain and are enrolled in hospice care are more likely to receive analgesics than those receiving traditional care, there is room for improvement. In NHs, 15% and 25% have untreated pain in long-term and short-term NH hospice, respectively. These estimates were derived from data sources >15 years old before Centers for Medicare and Medicaid Services (CMS) introduced pain quality indicators (2002), implemented Medicare Part D (2006), strengthened surveyor guidance (F-tag 309;2008), and overhauled pain measures on the Minimum Data Set (MDS) 3.0 in 2010.

Given wide changes in NH policy, we sought to update the estimates of pain prevalence and treatment in hospice-eligible NH residents and estimate the extent to which hospice enrollment increases pain management in dying NH residents with cancer pain, by leveraging national, comprehensive NH data from 2011 to 2012.

Methods

Data

We linked vital statistics of Medicare beneficiaries from the Medicare Master Beneficiary Summary File to the MDS 3.0 (2011 and 2012). The MDS 3.0 is a federally required, standardized assessment for all residents living in Medicare- or Medicaid-approved NHs (approximately 96% of U.S. NHs). The MDS includes over 450 items on NH residents’ functional status, mood, medical conditions, treatment provided, and other measures. Registered nurses at the NH facility review medical records, observe residents, and communicate with the resident and family members to complete the MDS. Comprehensive assessments are required at admission, annually, and at significant changes in health status including enrollment into hospice. Quarterly assessments (with a subset of items) are conducted every 90 days.

The University of Massachusetts Medical School Review Board approved this study.

Study Sample

We identified all Medicare beneficiaries with a validated date of death in 2011–2012 who had a comprehensive or quarterly MDS assessment ≤90 days before death (n = 656,202). MDS assessments completed after a resident’s death date were excluded. Residents with an active MDS diagnosis of cancer listed (Item 10100 or an ICD-9 code 140.xx-203.xx listed under 10800) were eligible (n = 88,888). We excluded 10,728 decedents who were ≤65 years of age (n = 5311), comatose (n = 429), or missing data on key variables (n = 4988). The source population included 78,160 residents. The last MDS assessment before death was used to measure hospice use, pain, pain management, and potential confounders.

Measuring Hospice Use

Hospice is available to all Medicare beneficiaries with a terminal illness and a life expectancy of less than six months. We assumed all in the source population were eligible for hospice. The NH nurse completing the last MDS assessment documented whether NH residents received state licensed and/or Medicare-certified hospice care in the previous 14 days (or since admission) while an NH resident or before admission/reentry (MDS 3.0 item O0100K2; Yes/No). If an NH resident received hospice care before NH entry and not during the NH stay, we did not consider them as having received hospice because of potential differences of hospice services in institutionalized settings. We did not exclude persons who received hospice care outside of the NH. Receipt of hospice care showed excellent agreement between research nurses and field nurses (κ = 0.89).

Pain and Pain Management

The outcomes of interest were pain and pain management at the last MDS assessment. All MDS 3.0 assessments collect information on pain presence, frequency, and severity within a five-day look-back period through either self-report when residents are able to be understood or through staff assessment. For residents who self-reported pain, frequency (rarely, occasionally, frequently, almost constantly) and severity of pain were collected. Severity was measured using either the Verbal Descriptor Scale which categorizes pain as mild, moderate, severe, or very severe/horrible or the Numeric Rating Scale which rates pain from mild to very/severe horrible pain on a scale from 0 to 10. A validated crosswalk was used to compare the two scales. We used the CMS quality indicator definition to classify self-reported pain. The three categories were no pain, mild/infrequent pain (mild-to-severe pain occurring rarely/occasionally), and moderate/severe pain (either moderate/severe pain occurring frequently or almost constantly or very severe/horrible pain occurring at any frequency). If NH staff assessed pain, the nurse reviewed the resident’s medical record, consulted other staff, and directly observed the resident to document pain indicators (crying, moaning, grimaces, etc.) and pain frequency in the previous five days (none, occurring one to two days, three to four days, or daily). We categorized staff-assessed pain as follows: no pain, infrequent pain (one to two days), or frequent pain (three or more days).

Pain management in the five days preceding the assessment was based on a medical record review
conducted by NH staff of medications and interventions prescribed with the goal of treating pain. Three items were available including receipt of 1) scheduled pain regimen, 2) any PRN pain medication, and 3) any nonpharmacological pain intervention (including biofeedback, massage, physical therapy, stretching and strengthening exercises, chiropractic, electrical stimulation, acupuncture, etc.). We categorized receipt of any pharmacologic pain intervention if the assessor recorded a scheduled pain regimen or PRN medication use. Because scheduled pain regimens and PRN medications are differing but complimentary strategies to managing cancer pain,30 we examined them separately. All measures of pain and pain management had excellent reliability (κ > 0.92).22

Potential Confounders

We evaluated resident characteristics that could potentially confound the relationship between receipt of hospice and pain/pain management. Sociodemographic characteristics included age (65–74 years, 75–84 years, ≥85 years), race/ethnicity (non-Hispanic white vs. other), and marital status (married vs. other). Length of NH stay (<90 days, ≥90 days), type of MDS assessment (admission, quarterly, annual, significant change in status), and whether the resident was dually eligible for Medicaid were considered. Behavioral characteristics included rejection of care in the previous week. Clinical characteristics included comorbidities associated with hospice enrollment (heart failure, dementia) or pain (e.g., hip fracture, diabetes), physical functioning, and cognitive impairment. Physical functioning was measured using the MDS-Activities of Daily Living (ADL) Self-Performance Hierarchy categorized as totally dependent (5–6) or not (0–4).25 Cognitive impairment was measured using the Cognitive Function Scale,26 which integrates the self-reported Brief Interview for Mental Status (BIMS) with the staff-assessed Cognitive Performance Scale (CPS) when residents could not complete the BIMS screener. We categorized residents by whether they were severely cognitively impaired (incomplete BIMS and a CPS score of [5 or 6] or not [BIMS 0–15 or CPS 0–4]).

Matching

Among those with documented pain, we used matching with replacement to group each resident receiving hospice to up to five residents not receiving hospice by 1) facility, 2) type of pain assessment received (e.g., whether the resident self-reported pain or had staff observe/assess their pain), and 3) weeks from last MDS assessment to death (±3 days).31 We matched on facility to reduce the potential for facility-level confounding and ascertainment bias in pain assessment.32 We matched on type of pain assessment (self-reporting or staff-assessed) because the MDS measures of pain frequency and severity differ. Residents unable to self-report may be more severely cognitively impaired and not comparable to residents who could self-report due to underascertainment and undertreatment of pain in this vulnerable subpopulation.24,33,34

Results

Fig. 1 shows the prevalence of pain for NH residents in the source population by type of pain assessment and hospice use. For residents able to self-report pain (Fig. 1, Panel A), hospice users were more likely to report any pain than nonhospice users (hospice: 59.9%, 95% CI = 59.3%–60.5%; nonhospice: 50.0%, 95% CI = 49.4%–50.6%). The overall difference was more strongly driven by differences in mild/infrequent pain (hospice: 38.2%, 95% CI = 37.6%–38.8%; nonhospice: 31.6%, 95% CI = 31.1%–32.2%) than moderate-
to severe pain (hospice: 21.7, 95% CI = 21.2–22.2; nonhospice: 18.4, 95% CI = 17.9–18.8). For residents with staff-assessed pain (Fig. 1, Panel b), the overall difference in pain observed (hospice: 63.7%, 95% CI = 62.8–64.6; nonhospice: 44.4%, 95% CI = 43.3–45.5%) was primarily driven by reports of frequent pain (hospice: 43.5%, 95% CI = 42.6–44.4; nonhospice: 27.3%, 95% CI = 26.3–28.3%) than infrequent pain (hospice: 20.2%, 95% CI = 19.4–20.9; nonhospice: 17.1%, 95% CI = 16.3–18.0%). Of those experiencing pain and included in the matched analysis (23,830 hospice users [55.5% of all hospice users] and 19,104 nonhospice users [44.5% of all nonhospice users]), 9064 hospice users were matched to 7904 nonhospice users sampled with replacement to create 9064 matched strata from 1578 nursing homes. Table 1 shows characteristics of the matched hospice users and nonhospice users by pain assessment type. Eighteen percent had staff-assessed pain. Median time from the last MDS assessment to death was 3.0 weeks for self-reporting residents (interquartile range, 1.7–5.3) and 0.9 weeks for staff-assessed residents (interquartile range, 0.3–2.1). Matched residents were predominately white regardless of pain

**Fig. 1. Prevalence of pain in source population of nursing home residents with cancer during the last 90 days of life (N=78,160) by hospice use and stratified by pain assessment type: a) residents who self-reported pain, and b) residents with staff-assessed pain.**
assessment type or hospice use. There were differences between residents who self-reported pain and residents with staff-assessed pain. Relative to those who self-reported pain, staff-assessed residents were older and more likely to have a significant change in status MDS assessment, extensive ADL compromise, severe cognitive impairment, and dementia. Hospice users had similar levels of severe cognitive impairment in comparison to nonhospice users (regardless of pain assessment type) but were more likely to have a significant change in status MDS assessment and be totally physically dependent. Hospice users (regardless of assessment type) were more likely to have anxiety disorders relative to nonusers but had similar prevalence of other comorbid conditions with the exception of surgical wounds in residents who self-reported pain only. In those who could self-report pain only, hospice users were more likely to have dual eligibility for Medicare/Medicaid and were less likely to have an admission/quarterly/annual MDS assessment or be married relative to nonusers. In those with staff-assessed pain only, hospice users were less likely to be long-term nursing home residents and have a quarterly or annual MDS assessment relative to nonusers.

Receipt of Pain Management

Table 2 shows the association of hospice use and receipt of pharmacologic and nonpharmacologic
pain management among residents with any pain documented by type of pain assessment. Overall, those receiving hospice had greater odds of receiving medication relative to those who did not receive hospice (aOR [self-reported] = 2.03, 95% CI = 1.72–2.39; aOR [staff-assessed] = 3.30, 95% CI = 2.14–5.09). Relative to those not receiving hospice, those who did were more likely to receive scheduled analgesics (aOR [self-reported] = 1.85, 95% CI = 1.73–1.97; 1.60, 95% CI = 1.48–1.73; aOR [staff-assessed] = 1.45, 95% CI = 1.28–1.65) and PRN medication (aOR [self-reported] = 1.31, 95% CI = 1.20–1.43, aOR [staff-assessed] = 1.66, 95% CI = 1.36–2.04). Nonpharmacologic pain management was less commonly used than medication hospice users were more likely to receive nonpharmacologic pain management relative to nonhospice users (aOR [self-reported] = 1.18, 95% CI = 1.11–1.26; aOR [staff-assessed] = 1.41, 95% CI = 1.23–1.61).

Table 3 shows the analysis stratified by length of NH stay. For residents who self-reported pain, hospice use was associated with receipt of scheduled analgesics in short-term residents (aOR [self-report] = 1.90, 95% CI = 1.75–2.05) and long-term residents (aOR [self-report] = 1.87, 95% CI = 1.46–2.39). Hospice use was associated with scheduled analgesics in residents with staff-assessed pain for short-term residents only (aOR [staff-assessed] = 1.45, 95% CI = 1.23–1.70).

In sensitivity analyses including only NH residents who self-reported severe pain or who had staff-assessed frequent pain, the association between hospice use and pain management remained for receiving any medication (aOR [self-reported] = 2.62, 95% CI = 1.76–3.91; aOR [staff-assessed] = 4.41, 95% CI = 2.03–9.58), scheduled analgesics (aOR [self-reported] = 1.71, 95% CI = 1.47–1.99; aOR [staff-assessed] = 1.46, 95% CI = 1.21–1.75), PRN medication (aOR [self-reported] = 1.61, 95% CI = 1.30–2.00; aOR [staff-assessed] = 1.48, 95% CI = 1.09–2.01), and nonpharmacologic pain management (aOR [self-reported] = 1.24, 95% CI = 1.07–1.45; aOR [staff-assessed] = 1.48, 95% CI = 1.09–2.01).

Analyses using only full MDS assessments showed no evidence that the effect estimates were confounded by arthritis or osteoporosis (data not shown).

### Discussion

To our knowledge, this is one of the first national and comprehensive studies to focus on hospice care and pain/pain management in NH residents with cancer at the end-of-life. We found that among residents who self-reported pain, hospice use was associated with receipt of analgesics including both scheduled and PRN medication in comparison to nonhospice residents. Untreated pain in hospice and nonhospice users was lower than previous estimates, but pain management strategies varied by hospice use and assessment type. The prevalence of pain in our source population was higher in NH residents receiving hospice care compared to residents not receiving hospice care.

The largest previous study of hospice and pain management in NHs using data from 1992 to 1996 found that untreated pain was 15% in hospice users and 23% in nonhospice users. Similarly, a study using national survey data from 2004 found that approximately 15% of hospice users had untreated pain. Our findings suggest that there was an increase in overall use of pharmacologic pain management in both hospice and nonhospice users. We are uncertain what may

### Table 2

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Hospice, %</th>
<th>Nonhospice, %</th>
<th>Crude OR (95% CI)</th>
<th>Adjusted OR (95% CI)</th>
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<tr>
<td>Self-reported pain assessment (7242 matched strata)</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Any pharmacologic pain management</td>
<td>97.1</td>
<td>94.4</td>
<td>1.99 (1.69–2.34)</td>
<td>2.03 (1.72–2.39)</td>
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<tr>
<td>Scheduled pain regimen</td>
<td>71.5</td>
<td>56.1</td>
<td>1.85 (1.74–1.97)</td>
<td>1.85 (1.73–1.97)</td>
</tr>
<tr>
<td>PRN medication</td>
<td>86.9</td>
<td>83.1</td>
<td>1.32 (1.21–1.44)</td>
<td>1.31 (1.20–1.43)</td>
</tr>
<tr>
<td>Nonpharmacologic pain management</td>
<td>45.1</td>
<td>41.1</td>
<td>1.19 (1.12–1.27)</td>
<td>1.18 (1.11–1.26)</td>
</tr>
<tr>
<td>Staff assessment (1822 matched strata)</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any pharmacologic pain management</td>
<td>98.4</td>
<td>95.2</td>
<td>3.24 (2.14–4.93)</td>
<td>3.30 (2.14–5.09)</td>
</tr>
<tr>
<td>Scheduled pain regimen</td>
<td>68.2</td>
<td>58.2</td>
<td>1.48 (1.30–1.68)</td>
<td>1.45 (1.28–1.65)</td>
</tr>
<tr>
<td>PRN medication</td>
<td>90.7</td>
<td>84.1</td>
<td>1.67 (1.37–2.04)</td>
<td>1.66 (1.36–2.04)</td>
</tr>
<tr>
<td>Nonpharmacologic pain management</td>
<td>50.8</td>
<td>40.3</td>
<td>1.41 (1.23–1.61)</td>
<td>1.41 (1.23–1.61)</td>
</tr>
</tbody>
</table>

OR = odds ratio.

*Adjusted for age, gender, and race/ethnicity.

7242 hospice users matched to 13,387 nonhospice users (6694 unique nonhospice users matched with replacement).

1822 hospice users matched to 2488 nonhospice users (1210 unique nonhospice users matched with replacement).
### Table 3
Association Between Hospice Use and Pain Management in Nursing by Length of Stay in Nursing Home Residents With Cancer Who Experienced Any Pain (6696 Matched Strata)\(^a\)

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Short-Term Resident (&lt;90 Days)</th>
<th>Long-Term Resident (≥90 Days)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Hospice, %</td>
<td>Nonhospice, %</td>
</tr>
<tr>
<td>Self-reported pain assessment (4752 short-term matched strata, 703 long-term matched strata)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any pharmacologic pain management</td>
<td>97.4</td>
<td>94.6</td>
</tr>
<tr>
<td>Scheduled pain regimen</td>
<td>68.9</td>
<td>52.4</td>
</tr>
<tr>
<td>PRN medication</td>
<td>89.4</td>
<td>87.2</td>
</tr>
<tr>
<td>Nonpharmacologic pain management</td>
<td>45.6</td>
<td>42.7</td>
</tr>
<tr>
<td>Staff pain assessment (1072 short-term matched strata, 169 long-term matched strata)(^b)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any pharmacologic pain management</td>
<td>98.0</td>
<td>95.6</td>
</tr>
<tr>
<td>Scheduled pain regimen</td>
<td>64.8</td>
<td>53.8</td>
</tr>
<tr>
<td>PRN medication</td>
<td>92.8</td>
<td>89.7</td>
</tr>
<tr>
<td>Nonpharmacologic pain management</td>
<td>52.4</td>
<td>41.2</td>
</tr>
</tbody>
</table>

\(^a\)OR = odds ratio.

\(^b\)Of the total 9064 matched strata, 2368 matched strata were not included in this analysis because of complete discordance of length of stay between hospice users and nonhospice users.

\(^c\)Adjusted for age, gender, and race/ethnicity.

\(^d\)For self-reported pain: the 4,752 short-term stay matched strata included 4,752 hospice users matched to 7,847 non-hospice users (4,342 unique non-hospice users matched with replacement). The 703 long-term stay matched strata included 703 hospice users matched to 833 non-hospice users (695 unique non-hospice users matched with replacement).

\(^e\)For staff-assessed pain: 1,072 short-term stay matched strata included 1,072 hospice users matched to 1,407 non-hospice users (708 unique non-hospice users matched with replacement). The 169 long-term stay matched strata included 169 hospice users matched to 186 non-hospice users (154 unique non-hospice users matched with replacement).

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The association between hospice and receipt of scheduled analgesics was strongest in hospice users, with the highest level of scheduled analgesics in short-term residents. This appears to be driven less by the high level of scheduled analgesics in short-term residents rather than high levels of scheduled analgesics in long-term residents who may not be able to independently provide pain management. The association between hospice use and receipt of scheduled analgesics was strongest in hospice users, with the highest level of scheduled analgesics in short-term residents. This appears to be driven less by the high level of scheduled analgesics in short-term residents rather than high levels of scheduled analgesics in long-term residents who may not be able to independently provide pain management. The association between hospice use and receipt of scheduled analgesics was strongest in hospice users, with the highest level of scheduled analgesics in short-term residents. This appears to be driven less by the high level of scheduled analgesics in short-term residents rather than high levels of scheduled analgesics in long-term residents who may not be able to independently provide pain management.
because hospice staff specialize in pain and symptom management and have experience treating patients that they have never seen before. The relative benefits of hospice care are largely present in long-term NH residents as well, although the overall use of scheduled analgesics increased regardless of hospice status.

In the source population, pain was reported in more than half of all NH residents with cancer at the end-of-life, and hospice users reported more pain than nonhospice users. Some of the differences in pain by hospice use may be due to how and when NH residents receive hospice care, as NH staff members have cited unmanageable pain as a common reason for referring residents to hospice. However, there is potential for ascertainment bias if residents receiving hospice were more likely to have their pain recorded, and this may be differential by pain assessment type. Residents who could self-report likely received a standardized pain interview from facility nurses administering the MDS assessment, but when pain was staff-assessed, hospice users may have received enhanced pain surveillance and that resulted in more pain recorded relative to nonusers. In this case, the frequency of pain and untreated pain may be underdocumented in nonhospice users with staff-assessed pain; this could have biased our findings toward the null for this subgroup.

This study has several strengths. It provides a needed update on pain management in hospice and nonhospice residents at the end-of-life that is specific to cancer; it includes a comprehensive, recent national sample of Medicare beneficiaries in NHs; it uses enhanced MDS 3.0 assessments with improved pain interviews. This study also has limitations. First, hospice users may have stronger desires for pain management than nonhospice users. However, in our sensitivity analyses, we found that the positive association between hospice and receiving analgesics was still present in those reporting the most pain (and hypothesized to most desire pain management). Furthermore, prior studies document that dying residents and their families desire effective pain management regardless of whether the resident is enrolled in hospice. Second, we could not evaluate specific pharmacologic and nonpharmacologic interventions received, and we could only comment on the use of general pain management strategies recorded in the MDS. Third, we lacked information on cancer type and severity, which may have implications for whether the pain experienced was due to cancer. However, pain management guidelines are not cancer specific and the outcomes we considered measured what should be minimally done for residents experiencing pain at the end of life. Fourth, we had limited information on hospice use and could not evaluate the potentially moderating effects of length of hospice stay.

Finally, this study only considered physical pain; psychological, existential, and spiritual pain were not considered.

Conclusion

The study provides an important update on pain management in NH residents at the end of life. Given that pain management is one of the primary goals of dying residents and their families, our finding that hospice use was associated with receiving pain management in residents with any reported or observed pain suggests that hospice care may contribute to a better quality of life at the end of life. We also found that untreated pain was lower than previous estimates for both hospice and nonhospice users, which may suggest that the overall quality of life for dying residents with cancer is improving. However, future work is needed to examine appropriateness of medications used, as the overall prevalence of pain was extensive.

Disclosures and Acknowledgments

The authors declare no conflict of interests.

This work was supported by the National Cancer Institute (grant 1R21CA198172) and the National Center for Advancing Translational Sciences (1TL1TR001454).

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