

A Cross-Sectional Analysis of the Prevalence of Undertreatment of Nonpain Symptoms and Factors Associated With Undertreatment in Older Nursing Home Hospice/Palliative Care Patients

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ABSTRACT

Background: Approximately 25% of all US deaths occur in the long-term care setting, and this figure is projected to rise to 40% by the year 2040. Currently, there is limited information on nonpain symptoms and their appropriate treatment in this setting at the end of life.

Objective: This study evaluated the prevalence of undertreatment of nonpain symptoms and factors associated with undertreatment in older nursing home hospice/palliative care patients.

Methods: This study used a cross-sectional sample of older (≥ 65 years) hospice/palliative care patients to represent all patients from the 2004 National Nursing Home Survey (NNHS) funded by the Centers for Disease Control and Prevention. Nonpain symptoms were determined from facility staff, who used the medical records to answer questions about the residents. Data on medication use were derived from medication administration records. *Undertreatment* was defined as the omission of a necessary medication for a specific nonpain symptom and was evaluated as a dichotomous variable (yes = the nonpain symptom was not treated with a medication; no = the nonpain symptom was treated with a medication). Cross-sectional bivariate analyses were conducted using χ^2 and regression coefficient tests to determine factors potentially associated with undertreatment of nonpain symptoms.

Results: The cross-sectional sample included 303 older nursing home hospice/palliative care patients from among the 33,413 (weighted) patients from the 2004 NNHS. Overall, most of the patients were white (91.4% [277/303]) and female (71.9% [218/303]), and nearly half were aged ≥ 85 years (47.9% [145/303]). One or more nonpain symptoms occurred in 82 patients (22.0% weighted). The most common nonpain symptoms (weighted percentages) were constipation/fecal impaction in 35 patients (8.8%), cough in 34 patients (9.2%), nausea/vomiting in 26 patients (7.2%), fever in 11 patients (3.1%), and diarrhea in 9 patients (1.9%). Medication undertreatment of any of the above symptoms was seen in 47 of 82 patients (60.0% weighted), ranging from a low of 26.4% for constipation/fecal impaction to a high of 88.0% for nausea/vomiting. Undertreated patients had significantly more problems with

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bed mobility (n [weighted %], 43 [92.3%] vs 21 [67.2%]; $P = 0.013$), mood (21 [44.7%] vs 7 [19.7%]; $P = 0.017$), and pressure ulcers (12 [25.7%] vs 2 [6.1%]; $P = 0.023$) than did treated patients. The undertreated group also had a significantly greater number of secondary diagnoses (weighted mean [SD], 6.5 [0.7] vs 5.2 [0.5]; $P = 0.004$) but had a shorter length of stay in hospice/palliative care (120.5 [20.1] vs 219.4 [51.8] days; $P < 0.001$) or in the nursing home (552.0 [96.5] vs 1285.4 [268.3] days; $P = 0.001$).

Conclusions: The prevalence of nonpain symptoms was low (22.0% weighted) in older nursing home hospice/palliative care patients. However, medication undertreatment of nonpain symptoms was seen in more than half of these patients. Future quality-improvement initiatives for nursing home hospice/palliative care patients are needed beyond the management of pain symptoms. (*Am J Geriatr Pharmacother.* 2010;8:225–232) © 2010 Excerpta Medica Inc.

Key words: long-term care, nursing homes, palliative care, hospice care, aged.

INTRODUCTION

According to the US Census Bureau, with the aging of the “baby boom” generation and the linear increase in life expectancy over the past century, older adults are the fastest-growing segment of the population.¹ In 2002, individuals aged ≥ 65 years made up 12.5% of the population. By the year 2050, however, 20% of the population is expected to be aged ≥ 65 years. As people age, they will develop chronic diseases,^{2,3} and many will enter nursing home facilities for custodial and, eventually, end-of-life care.^{4–6} In 1994, ~25% of Americans who died were in long-term care facilities, and this proportion is projected to increase to 40% by the year 2040.⁶

Studies have shown that we have very little knowledge about the dying experience of older adults^{7,8} and even less empiric evidence regarding how palliative or hospice care is delivered in the nursing home setting.⁹ One concern is the potential underutilization of medications (ie, omission of necessary medication for a diagnosed condition) in nursing home hospice/palliative care patients.¹⁰ One large observational study reported that, on average, 50% of cancer patients who die in US nursing homes experience severe pain.³ Hospice enrollment improves pain assessment and management; however, treatment of pain is woefully inadequate, even in this patient population.^{11,12} A cross-sectional study of older adults ($n = 107$) in nursing homes reported that there was no statistically significant difference between

hospice and nonhospice residents in the prescription and administration of pain medications.¹³

Currently, at least 2 guidelines exist that can be used for the pharmacologic treatment of nonpain symptoms.^{14,15} Unfortunately, although research has been conducted on the recognition and management of pain in hospice care in nursing home settings,^{11–13} no such studies have been conducted regarding common nonpain symptoms occurring at the end of life, such as constipation/fecal impaction, cough, nausea/vomiting, fever, and diarrhea. The objective of this study was to evaluate the prevalence of undertreatment of nonpain symptoms and factors associated with undertreatment in older nursing home hospice/palliative care patients.

METHODS

Study Design, Source of Data, and Sample

This cross-sectional study used information derived from the resident file of the 2004 National Nursing Home Survey (NNHS).^{16,17} The NNHS was conducted by the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC). The present study sample included patients aged ≥ 65 years who were assigned to a bed on a hospice specialty unit or were receiving services from a special program for hospice, palliative, or end-of-life care. The nursing home staff was interviewed to gather this information for all 13,507 patients in the 2004 NNHS. An example of an affirmative response (ie, hospice and palliative care established in a nursing home, as opposed to a different setting) would be someone who was receiving hospice/palliative care at home and then was transferred to a nursing home to continue this care.

This study was approved by the University of Pittsburgh institutional review board.

Data Collection and Management

The 2004 NNHS achieved a 78% response rate that included 13,507 patients from 1174 nursing homes, representing a population of ~1.5 million patients. For the present study, a representative sample of nursing homes was selected from a total of ~18,000 nursing home facilities in the United States. The nursing homes were selected using systematic sampling with a probability proportional to bed size. The data were collected from a total of 1500 US nursing homes and included up to 12 current patients per nursing home.

Patient data were collected on-site in the nursing homes by computer-assisted interviews of designated staff members familiar with the specific sampled patients and their care. The designated staff members

were asked to use the residents' medical records or Minimum Data Set (MDS) information¹⁸ to answer the survey questions.¹⁹ The facility respondent who was familiar with the residents and their care was selected by the nursing home administrator to answer the questions in the resident-level modules.¹⁶ The patients' sociodemographic characteristics and health status data were collected by deriving information from the MDS evaluations. Information about source of payments for nursing home care and recent use of health care services was also collected. For medication information, trained interviewers employed by the CDC NCHS extracted the names of up to 25 medications administered in the previous 24 hours (including both regularly scheduled and as-needed medications) from the patients' medication administration records.^{16,19} Regarding prescribed medications, the following questions were asked: (1) "What medications were taken by the resident during the 24 hours of the day before the facility interview, including standing or routine medications or PRN (ie, as needed) medications?" and (2) "What medications were taken regularly by the resident but not during the 24 hours of the day before the facility interview, including standing orders for administration only, but excluding PRN medications?"¹⁶ For example, relevant to this study was whether a patient had a standing order for an oral laxative. If the patient had had no bowel movement in the previous 3 days, then this medication use or administration would be captured.

Outcome Measures

MDS data in the NNHS¹⁷ were used to abstract information on the presence or absence of the following symptoms: constipation/fecal impaction, cough, nausea/vomiting, fever, and diarrhea. These symptoms were chosen because, in all cases, medication treatment guidelines are available.^{14,15} Nonpain symptoms were determined from facility staff, who used the medical records to answer questions about the residents. The lead-in question for nonpain symptoms from the NNHS was as follows: "Please look at this card and tell me what types of symptoms he/she has."^{16,19} Symptoms on the card included those indicated above (ie, constipation/fecal impaction, cough, nausea/vomiting, fever, diarrhea). As stated earlier, medication use was determined from medication administration records. Prescribed medications were categorized according to the National Drug Code¹⁶ Therapeutic Subclass Codes and were linked to potential medical indications (eg, anti-pyretics [1728], NSAIDs [1727], laxatives [0876], cough suppressants [1943], analgesics or narcotics [opioids]

[1721], anti-diarrheals [0875], antiemetics [0635]). The definition of cough suppressants also included opioids contained in analgesics because they have cough-suppressant properties. NSAIDs were included with anti-pyretics because they also reduce fever.

Undertreatment was operationally defined as the omission of a necessary medication for a specific non-pain symptom and was evaluated as a dichotomous variable (yes = the nonpain symptom was not treated with a medication; no = the nonpain symptom was treated with a medication). For example, a patient with constipation/fecal impaction who did not receive a laxative would be classified as being undertreated.

Independent Variables

Sociodemographic data were collected including age, sex, marital status, race and ethnicity, and veteran status. Health status characteristics included dichotomous measures for comatose status, extensive or total dependence in 4 basic activities of daily living (ie, bed mobility, transfer, eating, toileting), mood problems, behavior problems, pressure ulcer, bowel incontinence, urinary incontinence, and falls during the past 6 months. Dichotomous measures for the primary diagnosis at the time of nursing home admission were also created based on the *International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM) codes*.²⁰ A physician (E.J.J.) grouped the individual diagnoses into organ systems using *ICD-9-CM codes*. Continuous measures were created for the number of primary and secondary diagnoses.

Characteristics that may affect access to health care were represented by dichotomously scored (1 = yes; 0 = no) variables for the source of payment for nursing home care (ie, government, self-pay, other). Continuous measures were also created for the number of hospitalizations and emergency department visits in the previous 90 days and the length of stay (in days) in hospice/palliative care and in a nursing home. Finally, a dichotomous measure was created to indicate whether hospice/palliative care was established in the nursing home.

Statistical Analysis

All data were analyzed using the weights provided by the NNHS to adjust for the complex sampling design used by the NNHS. The subset of data for the subpopulation of interest (ie, aged ≥ 65 years and in hospice/palliative care) was selected through domain analysis to avoid affecting the provided sampling weights. The data were summarized by percentages and means (SDs) for all variables. For descriptive purposes, non-

pain symptom prevalence and pharmacologic treatment were identified separately. Cross-sectional bivariate analyses were conducted using χ^2 and regression coefficient tests to determine factors potentially associated with undertreatment of nonpain symptoms (yes/no). All bivariate analyses were conducted using the SURVEYREG procedure to compare continuous variables (ie, t test) and the SURVEYFREQ procedure to compare all categorical variables (ie, χ^2 test) in SAS version 9.2 software (SAS Institute Inc., Cary, North Carolina).

RESULTS

The study group included 303 older nursing home hospice/palliative care patients, representing 33,413 weighted patients from the overall sample of 13,507 residents in the CDC-funded 2004 NNHS. **Table I** lists the characteristics of the 303 patients. Only 12 of 303 patients (4.0%) were assigned to a hospice specialty unit; the remaining 292 patients (96.4%) received hospice/palliative care that was not defined by a physically distinct unit (1 patient answered "yes" for both questions). Overall, 91.4% (277/303) of the patients were white, 71.9% (218/303) were female, and 47.9% (145/303) were aged ≥ 85 years.

Table II shows that one or more of the nonpain symptoms occurred in 82 of the 303 patients (22.0% weighted). The most common nonpain symptoms (weighted percentages) were constipation/fecal impaction in 35 patients (8.8%), cough in 34 patients (9.2%), nausea/vomiting in 26 patients (7.2%), fever in 11 patients (3.1%), and diarrhea in 9 patients (1.9%).

Table III shows the rates of pharmacologic undertreatment among those patients with the 5 nonpain symptoms. Medication undertreatment of any of the symptoms was seen in 47 of 82 patients (60.0% weighted), ranging from a low of 8 of 35 (26.4% weighted) for constipation/fecal impaction to a high of 22 of 26 (88.0% weighted) for nausea/vomiting.

Table IV compares the undertreated and treated groups for statistically significant variables ($P < 0.05$ for each) using bivariate comparisons with χ^2 test for categorical variables and t test for continuous measures. Undertreated patients had significantly more problems with bed mobility (n [weighted %], 43 [92.3%] vs 21 [67.2%]; $P = 0.013$), mood (21 [44.7%] vs 7 [19.7%]; $P = 0.017$), and pressure ulcers (12 [25.7%] vs 2 [6.1%]; $P = 0.023$) than did the treated patients. The undertreated group also had a significantly greater number of secondary diagnoses (mean [SD], 6.5 [0.7] vs 5.2 [0.5]; $P = 0.004$) but had a shorter length of stay in hospice/

palliative care (120.5 [20.1] vs 219.4 [51.8] days; $P < 0.001$) or in the nursing home (552.0 [96.5] vs 1285.4 [268.3] days; $P = 0.001$).

DISCUSSION

To the best of our knowledge, this is the first national study to examine the pharmacologic undertreatment of nonpain symptoms in older nursing home hospice/palliative care patients. These results indicate that the reported prevalence of nonpain symptoms in older nursing home hospice/palliative care patients was low (22.0% weighted). Although there is little existing research in this area, a small study by Hall et al²¹ examined the medical records of 185 residents who died in 5 long-term care facilities in Canada. Focusing on the last 48 hours of life, they found that nonpain symptoms included 24% with fever. No information was provided about undertreatment of fever or other common symptoms such as constipation, cough, nausea/vomiting, or diarrhea.

In a nationwide observational study, Brandt et al²² reported on 544 terminally ill patients residing in 16 nursing homes in the Netherlands. Nonpain symptoms varied depending on the underlying diseases and included fever in 10.0% to 23.7% of patients and nausea and vomiting in 0.9% to 13.3%. Brandt et al²³ also studied symptoms in 253 nursing home patients who were conscious 24 to 48 hours before death; coughing was reported in 14%. Although rates of constipation have been reported to be as high as 45%²⁴ and diarrhea as low as 7% to 10% in terminally ill patients,²⁵ rates in nursing home hospice/palliative care patients have not been reported. Thus, very little is known about this growing population of potentially vulnerable patients.

Despite the low reported prevalence of nonpain symptoms in older nursing home hospice/palliative care patients in the present study, medication undertreatment of nonpain symptoms was seen in more than half of these patients (60.0% weighted). Although medication intake generally increases with age,²⁶ the literature shows that underuse of medications or the omission of drug therapy that is indicated for the treatment or prevention of a disease or condition is an important and increasingly recognized problem, occurring in 55% to 64% of older adults.²⁷⁻²⁹

The findings in the present study suggest that those nursing home hospice/palliative care patients who were more debilitated, as indicated by higher rates of problems with bed mobility, mood, pressure ulcer, and comorbid conditions, were more likely to have suboptimal treatment of nonpain symptoms. Because of limitations

Table I. Characteristics of older nursing home hospice/palliative care patients (unweighted sample, n = 303; representing N = 33,413 patients). Data are expressed as unweighted number (weighted %), except as indicated.

Characteristic	Result	Characteristic	Result
Sociodemographic		Health status (continued)	
Age group, y		Primary diagnosis	
65–74	40 (13.2)	Cancer	33 (11.4)
75–84	118 (38.9)	Cardiac	44 (15.2)
≥85	145 (47.9)	Gastrointestinal	11 (3.8)
Female sex	218 (71.9)	Genitourinary	7 (2.4)
Married	80 (26.4)	Hematologic	6 (2.1)
Race		Metabolic	11 (3.8)
White	277 (91.4)	Musculoskeletal	12 (4.2)
Black	20 (6.6)	Neuropsychiatric	112 (38.8)
Other	6 (2.0)	Pulmonary	41 (14.2)
Hispanic/Latino ethnicity	5 (1.7)	Other	12 (4.2)
Veteran	21 (6.9)	No. of secondary conditions, weighted mean (SD)	5.45 (3.3)
Health status		Factors that may affect access to health care	
Comatose	6 (2.0)	Payment source	
Dependence in basic activities of daily living		Government	171 (56.5)
Bed mobility	248 (81.8)	Self-pay	88 (30.8)
Transfer	260 (85.8)	Other	44 (12.7)
Eating	187 (61.7)	No. of hospitalizations, weighted mean (SD)	1.50 (0.9)
Toileting	277 (91.4)	No. of emergency department visits, weighted mean (SD)	1.21 (0.5)
Mood problem	72 (24.2)	Length of stay in hospice/palliative care, weighted mean (SD), d	146.30 (135.2)
Behavior problem	89 (30.0)	Length of stay in nursing home, weighted mean (SD), d	687.23 (791.2)
Pressure ulcer	60 (19.8)	Hospice/palliative care established in nursing home	250 (81.9)
Bowel incontinence	209 (31.0)		
Urinary incontinence	228 (24.8)		
Falls	89 (40.6)		

Table II. Prevalence of nonpain symptoms in older nursing home hospice/palliative care patients (unweighted sample, n = 303; representing N = 33,413 patients).

Symptom	Unweighted No.	Weighted %
Constipation/fecal impaction	35	8.8
Cough	34	9.2
Nausea/vomiting	26	7.2
Fever	11	3.1
Diarrhea	9	1.9
Any of the above	82	22.0

Table III. Pharmacologic undertreatment of nonpain symptoms in older nursing home hospice/palliative care patients.

Symptom	Unweighted No.	Weighted %
Constipation/fecal impaction (n = 35)	8	26.4
Cough (n = 34)	24	69.3
Nausea/vomiting (n = 26)	22	88.0
Fever (n = 11)	7	80.5
Diarrhea (n = 9)	8	73.8
Any of the above (n = 82)	47	60.0

Table IV. Comparison of groups with undertreated versus treated nonpain symptoms among older nursing home hospice/palliative care patients by specific variables. Data are expressed as unweighted number (weighted %), except as indicated.

Variable	Undertreated Group (n = 47)	Treated Group (n = 35)	p*
Bed mobility problem	43 (92.3)	21 (67.2)	0.013
Mood problem	21 (44.7)	7 (19.7)	0.017
Pressure ulcer problem	12 (25.7)	2 (6.1)	0.023
No. of secondary conditions, weighted mean (SD)	6.5 (0.7)	5.2 (0.5)	0.004
Length of stay in hospice/palliative care, weighted mean (SD), d	120.5 (20.1)	219.4 (51.8)	<0.001
Length of stay in nursing home, weighted mean (SD), d	552.0 (96.5)	1285.4 (268.3)	0.001

*Bivariate comparisons were made with χ^2 test for categoric variables and t test for continuous measures.

in the availability of data, caution must be used in drawing firm conclusions regarding the associations between nonpain symptom management and these various measures. It is possible that these debilitated patients were less communicative about their symptoms or that staff members had inaccurate perceptions about the patients' degree of suffering or discomfort. Patients with depressive symptoms may also be less likely to report nonpain symptoms or to request medications that are usually ordered on an as-needed basis. It is also possible that nursing home staff members who were engaged in the time-consuming care of pressure ulcers had little available time to assess and address symptoms that were not immediately apparent. The study finding that a longer stay in hospice/palliative care or in the nursing home was associated with greater treatment of nonpain symptoms is logical, because health care providers would have had more time to address this important quality-of-care issue.

The length of stay in hospice/palliative care found in this study is relatively long compared with the average outpatient hospice length of stay. In the 2004 NNHS,¹⁹ 65% of responding outpatient hospice and palliative care organizations offered care to patients for a mean of 36 to 63 days; 18% of the organizations had an average patient stay of 43 to 49 days; and 17% had patients who stayed 50 to 56 days. Given that only 20% of the organizations had an average length of stay of >64 days, the industry should focus on educating physicians and the community about the benefits of end-of-life care. Another important topic includes chronic comorbid medical conditions, which are frequently encountered in patients with life-limiting illness.³⁰ It has been argued that the management of comorbid conditions should be actively reviewed in response to the systemic changes encountered in the palliative phase of a life-limiting illness.^{31,32}

This study had several limitations. First, because it was a cross-sectional study, causal relationships cannot be determined. Second, because of how the survey questions were asked, the patients could not be separated into those receiving hospice care and those receiving palliative care. Third, the data did not allow reporting of nonpain symptom severity. Fourth, data were not available to determine whether allergies or a contraindication to a class of medications resulted in undertreatment of nonpain symptoms. Fifth, because of the relatively small sample size, it was not possible to conduct meaningful multivariable analyses.

CONCLUSIONS

The prevalence of nonpain symptoms in older nursing home hospice/palliative care patients was low (22.0% weighted). However, medication undertreatment of nonpain symptoms was seen in more than half of these patients. Future quality-improvement initiatives for nursing home hospice/palliative care patients are needed beyond the management of pain symptoms.

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