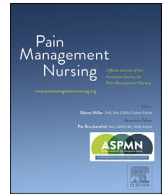




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## Original Research Article

## Pain Management in Home Health Care: Relationship With Dementia and Facility Admissions



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## ABSTRACT

**Background:** Pain is common yet under-studied among older Medicare home health (HH) patients with Alzheimer's disease and related dementias (ADRD).

**Aims:** Examine (1) the association between ADRD and severe pain in Medicare HH patients; and (2) the impact of severe pain and ADRD on unplanned facility admissions in this population.

**Design:** Analysis of the Outcome and Assessment Information Set (OASIS) and Medicare claims data.

**Settings/Participants:** 6,153 patients ≥65 years receiving care from a nonprofit HH agency in 2017.

**Methods:** Study outcomes included presence of severe pain and time-to-event measures of unplanned facility admissions (hospital, nursing home, or rehabilitation facilities). ADRD was identified using ICD-10 diagnosis codes and cognitive impairment symptoms. Logistic regression and Cox proportional hazard models were used to examine, respectively, the association between ADRD and severe pain, and the independent and interaction effects of severe pain and ADRD on unplanned facility admission.

**Results:** Patients with ADRD (n = 1,525, 24.8%) were less likely to have recorded severe pain than others (16.4% vs. 23.6%,  $p < .001$ ). Adjusting for demographics, comorbidities, mental and physical functional status, and use of HH services, having severe pain was related to a 35% increase (hazard ratio [HR] = 1.35,  $p = .002$ ) in the risk of unplanned facility admission, but the increase in such risk was the same whether or not the patient had ADRD.

**Conclusions:** HH patients with ADRD may have under-recognized pain. Severe pain is a significant independent predictor of unplanned facility admissions among HH patients.

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## Background

Pain can contribute to the neuropsychiatric symptoms in Alzheimer's disease and related dementias (ADRD), including aggression, agitation, hallucinations, delusions (Corbett et al., 2012; Malara et al., 2016), and depression (Wang et al., 2017). Untreated pain can also result in several unfavorable outcomes, including impaired physical function (Smith et al., 2016), poorer quality of life

(O'Sullivan et al., 2016), hospitalizations (Kang et al., 2017) and mortality (Smith et al., 2018). Yet pain assessment is challenging among people with ADRD, because they are less likely to self-report pain than people with intact cognition (Husebo et al., 2016). Changes in the ability to self-report pain in people with ADRD could be related to neurobiological alterations in sensory and affective regions of the brain (Monroe et al., 2017). It is therefore critical to regularly and proactively screen patients with ADRD for pain.

Home health (HH) care is commonly used among older adults with ADRD in the United States. National data showed that among adults  $\geq 65$  years old who developed moderately severe dementia in 2012–2016, 64% received care at home (Harrison et al., 2019). In 2017, 3.4 million Medicare beneficiaries received HH care (Medicare Payment Advisory Commission, 2019), including one third who had ADRD and cognitive impairment (Harris-Kojetin et al., 2016). Compared with nursing home residents with ADRD, older adults with ADRD living at home report more bothersome pain (Harrison et al., 2019). Additionally, nurses caring for older adults with ADRD express having difficulty in recognizing pain (Monroe et al., 2015). This finding highlights the importance of appropriate pain assessment in HH recipients with ADRD.

Effective detection and management of pain are core functions of HH care. The Outcome and Assessment Information Set (OASIS)—a standardized tool used by all Medicare-certified HH agencies to collect multidimensional patient information—includes assessments of pain. In a national survey of patient experience with HH care, patient response to the question “In the last 2 months of care, did you and a home health provider from this agency talk about pain?” is a core measure of HH care quality (Centers for Medicare & Medicaid Services [CMS], 2019a). Moreover, HH care facilitates early detection of pain through the use of home-based telehealth monitors (Dobscha et al., 2006). Pain management is also often emphasized in studies aimed at improving HH care outcomes (Smith et al., 2016).

Several studies with nursing home residents noted lower rates of reported pain among those with ADRD than those without (Ferrell et al., 1995; Sengstaken & King, 1993; Wu et al., 2005), which suggests possible under-recognition of pain related to ADRD. Further, because patients with ADRD may be less likely to receive appropriate treatment for pain than those without ADRD (Monroe et al., 2014), the negative impact of pain on health outcomes may be greater in patients with ADRD relative to those with intact cognition. Although older HH recipients do not have access to regular pain assessment as nursing home residents do, they may be experiencing prevalent pain (Harrison et al., 2019). To date, no studies have examined the relationship between having ADRD and reported pain, and the impact of pain on health outcomes among older HH recipients with and without ADRD.

The objectives of this study were to examine: (1) the association between ADRD and having constant severe interfering pain (hereafter referred to as “severe pain”) in older Medicare HH recipients; and (2) the impact of severe pain on unplanned facility admissions (hospital, rehabilitation facility, and nursing home) among older HH recipients with and without ADRD. We hypothesized that HH recipients with ADRD will have a lower recorded rate of severe pain than those without ADRD, and that having severe pain will result in increased risk of unplanned facility admissions in HH recipients, especially among patients with ADRD.

## Methods

### Data Sources and Study Population

This study used existing OASIS assessments and Medicare HH claims of a large nonprofit HH agency in New York that provides 450,000 home visits annually. The study population included

adults  $\geq 65$  years old receiving HH care from this agency in 2017. No additional eligibility criteria were used. OASIS is a standardized tool used by all Medicare-certified HH agencies to collect multidimensional patient information and outcomes, including demographics, living arrangement, health status, cognitive and physical function, severity and interference of pain, and healthcare facility admissions. Most OASIS items have well-validated psychometric properties, particularly the cognitive and physical function domains (Cronbach's  $\alpha = 0.86$ – $0.91$ ; Cohen's  $k = 0.4$ – $1.0$ ; Madigan & Fortinsky, 2001; O'Connor & Davitt, 2012).

### Variables

#### Outcomes

Study outcomes were presence of severe pain and unplanned facility admissions. We identified the presence of “severe pain” if the response was “all of the time” to the question about “frequency of pain interfering with patient's activity or movement” (M1242). The data sources for this variable include patient/caregiver interview, observation of nonverbal indicator of pain, physical assessment, information about the history of pain and use of pain medications in documents, and use of standardized, validated pain assessment tools (M1240).

Unplanned admission to healthcare facilities include hospitals, nursing homes, and inpatient rehabilitative facilities, whichever came first, during an HH episode of care. This outcome was identified by the OASIS items on facility admission (M2410) and reasons (M2430; excluding scheduled treatment/procedure). We counted only the first facility admission in the indexed HH admission period. Facility admission was operationalized as a time-to-event variable (number of days from HH start date to the first facility admission date) in analysis.

#### Independent Variable

Our primary independent variable was the presence of ADRD, identified by having a diagnosis of ADRD in ICD-10 diagnoses codes (F00, F01, F02, F03, G30, G31.0, G31.83 in HH claims) or cognitive impairment (four OASIS start-of-care items on cognitive function). Cognitive impairment was identified if the patient had the selected rating (noted by HH clinician) to any of the following items: (1) current cognitive functioning (M1700: “constant disorientation that leads to dependence more than half of the time or all the time”); (2) frequency of confusion (M1710: “constantly/daily”); (3) memory deficit (M1740-1: “significant memory loss that requires supervision”); and (4) impaired decision-making (M1740-2: “failure to perform usual [instrumental] activities of daily living [ADL/IADL] due to significant impairment on one's decision-making ability”).

To determine if pain is a predictor for unplanned facility admissions, we also included presence of severe pain as an independent variable.

#### Covariates

Demographics, health status, caregiving support, and intensity of HH service are related to facility admissions, and thus were included as covariates (Lohman et al., 2017; Wang et al., 2019; Wang et al., 2018).

#### Demographics

Demographics included age, sex, race/ethnicity, marital status, living arrangement (alone at home/with others at home/aggregated settings), and dual Medicare and Medicaid eligibility. Race/ethnicity included non-Hispanic Caucasian, African American,

Hispanic, and Other (including Asian [2.4%], Native Hawaiian/Pacific Islander [0.28%], American Indian/Alaska Native [0.47%]).

### Health Status

Health status included: (1) number of ICD-10 diagnoses documented in Medicare HH claims (range: 0–15); (2) number of medications; (3) specific medical conditions that are related to facility admissions (i.e., heart failure, diabetes, chronic obstructive pulmonary disease, osteoarthritis, lower extremity joint replacement, and cancer); (4) obesity (M1036); (5) current smoking (M1036); (6) depression (having a depression diagnosis [ICD-10 code]; Patient Health Questionnaire-2 score of  $\geq 3$  [M1730], or physician-prescribed depression intervention [M2250]); (7) exhaustion (M1033); and (8) physical function (composite score of ADL limitations [M1800–1870]; Madigan et al., 2012).

### Caregiver Support

Caregiver support was defined as receiving daily assistance with ADL/IADL from informal caregivers (M2102; Yes/No).

### HH Intensity

We measured the intensity of HH services, including skilled nursing (SN), physical therapy (PT), occupational therapy (OT), social work (SW), and HH aide assistance (HA), as the number of reimbursed visits per week in Medicare HH claims. The formula was  $[(\text{total number of visits})/(\text{number of days receiving HHC})]*7$ , which has shown to be a robust measure of HH dosing in prior research (Madigan et al., 2012). HH intensity variables of SN, PT, and OT were categorized into quartiles in the multivariate models. Additionally, due to the low percentages of receiving SW (8%) and HA (10%), we used “receiving any SW” and “receiving any HA” instead of SW and HA intensities in the multivariate models.

### Statistical Analysis

Descriptive statistics were used to summarize sample characteristics as means (standard deviations [SD]) or median (interquartile range) for continuous variables and frequency (% [N]) for categorical variables. To address objective 1, we examined the

**Table 1**  
Sample Characteristics

Variable	Overall Sample (6,153)	Cohorts based on Alzheimer's Disease and Related Dementia (ADRD) and Severe Pain				p Value*
		No ADRD		Having ADRD		
		No Severe Pain	Severe Pain	No Severe Pain	Severe Pain	
		3,538 (57%)	1,090 (18%)	1,275 (21%)	250 (4%)	
Age, mean (SD)	80.1 (9.47)	79.2 (9.34)	76.8 (8.64)	84.9 (8.66)	81.8 (9.39)	<.0001
Female, n (%)	3,555 (58%)	1,957 (55%)	681 (63%)	753 (59%)	164 (66%)	<.0001
Married, n (%)	2,721 (44%)	1,596 (45%)	532 (49%)	502 (39%)	91 (36%)	<.0001
Race/ethnicity, n (%)						
Non-Hispanic White	5,323 (87%)	3,042 (86%)	943 (86.5%)	1,116 (87%)	222 (89%)	
African American	654 (10%)	404 (11.4%)	115 (10.5%)	115 (9%)	20 (8%)	
Hispanic	100 (2%)	50 (1.4%)	21 (2%)	23 (2%)	6 (2%)	
Other (e.g., Asian)	76 (1%)	42 (1.2%)	11 (1%)	21 (2%)	2 (1%)	.18
Living arrangement, n (%)						
Living with others	3,728 (60%)	2,160 (61%)	733 (67%)	698 (55%)	137 (55%)	
Living alone	1,761 (29%)	1,141 (32%)	312 (29%)	241 (19%)	67 (27%)	
Congregate settings (i.e., assisted living/residential care facilities)	664 (11%)	237 (7%)	45 (4%)	336 (26%)	46 (18%)	<.0001
Medicare-Medicaid dual eligibility, n (%)	148 (2%)	96 (3%)	24 (2%)	16 (1%)	12 (5%)	.002
Referral source						<.0001
After acute hospitalization	3,829 (62%)	2,352 (66%)	744 (68%)	609 (48%)	124 (49%)	
After post-acute care (skilled nursing/inpatient rehabilitation facilities)	768 (13%)	425 (12%)	117 (11%)	184 (14%)	42 (17%)	
Community	1,556 (25%)	761 (21%)	229 (21%)	482 (38%)	84 (34%)	
Number of diagnoses, mean (SD)	9.2 (3.46)	9.1 (3.47)	8.8 (3.49)	9.6 (3.34)	10.0 (3.47)	<.0001
Number of medications, mean (SD)	13.0 (5.61)	12.9 (5.54)	13.9 (5.64)	11.9 (5.48)	14.7 (6.19)	<.0001
Heart failure, n (%)	1,208 (20%)	780 (22%)	157 (14%)	217 (17%)	54 (22%)	<.0001
Chronic obstructive pulmonary disease, n (%)	1,104 (18%)	702 (20%)	152 (14%)	195 (15%)	55 (22%)	<.0001
Diabetes, n (%)	1,909 (31%)	1,173 (33%)	309 (28%)	350 (27%)	77 (31%)	<.0001
Osteoarthritis, n (%)	1,776 (29%)	972 (27%)	389 (36%)	341 (27%)	74 (30%)	<.0001
Joint replacement, n (%)	831 (14%)	443 (12%)	341 (31%)	24 (2%)	23 (9%)	<.0001
Cancer, n (%)	618 (10%)	423 (12%)	89 (8%)	87 (7%)	19 (8%)	<.0001
Current smoking, n (%)	1,150 (19%)	735 (21%)	167 (15%)	203 (16%)	45 (18%)	<.0001
Exhaustion, n (%)	3,790 (62%)	2,201 (62%)	666 (61%)	754 (59%)	169 (68%)	.052
Obesity, n (%)	1,368 (22%)	806 (23%)	296 (27%)	200 (16%)	66 (26%)	<.0001
Depression, n (%)	2,876 (46%)	1,471 (42%)	486 (45%)	756 (59%)	163 (65%)	<.0001
Composite ADL limitation score, mean (SD)	4.1 (1.28)	3.8 (1.21)	4.2 (1.01)	4.7 (0.37)	.9 (1.35)	<.0001
Having daily caregiver assistance with ADL, n (%)	5,129 (83%)	2,846 (80%)	926 (85%)	1,149 (90%)	208 (83%)	<.0001
Days of index home health admission (median, Q <sub>1</sub> , Q <sub>3</sub> )	29 (17, 48)	28 (16, 47)	29 (18, 43)	30 (18, 50)	33 (19, 55)	.65
Intensity of home health services in number of visits per week, mean (SD)						
Skilled nursing	1.8 (1.79)	1.9 (1.79)	1.5 (1.51)	1.7 (2.02)	1.6 (1.55)	<.0001
Physical therapy	1.2 (1.18)	1.1 (1.18)	1.5 (1.28)	1.2 (1.08)	1.3 (0.98)	<.0001
Occupational therapy	0.3 (0.59)	0.3 (0.59)	0.3 (0.53)	0.3 (0.62)	0.4 (0.72)	.0001
Social work	0.03 (0.019)	0.02 (0.10)	0.04 (0.36)	0.03 (0.14)	0.06 (0.27)	.0007
Aide assistance	0.15 (0.88)	0.13 (0.76)	0.2 (1.01)	0.2 (0.64)	0.3 (2.07)	.019

ADL = activities of daily living; SD = standard deviation.

\* p value of two-sided omnibus ANOVA test for continuous variables and chi square test for categorical variables.

relationship between ADRD and severe pain using logistic regression, adjusting for other covariates. To address objective 2, we modeled time-to-event measure of the unplanned facility admission against severe pain and ADRD using survival analysis (i.e., Cox proportional hazard models) adjusting for covariates. Cox proportional hazard models control for the variance in time-to-event of the outcome (i.e., number of days from the start of observation [HH admission] to the occurrence of such outcome), which provides more information than the binary outcome (Y/N). In addition, the models take into account right censoring when patient outcome is not observed at the end of the study period.

In the final model, we included severe pain, ADRD, and the interaction term between the two to understand the independent effect of severe pain on unplanned facility admission, and if differences exist in such an effect between patients with and those without ADRD. After we controlled for patient covariates and HH intensity variables (i.e., SN, PT, OT, SW, HA), the time-independent assumption of Schoenfeld residual of the final multivariate Cox Proportional Hazard model was met, that is, the slope in the generalized linear regression of the scaled Schoenfeld residuals was not significantly different from zero ( $p > .05$ ). Statistical analyses were conducted using Stata 15.1 (College Station, TX).

## Results

The study sample included 6,153 HH patients who on average were 80.1 years old, were primarily white (87%), female (58%), not married (56%), and referred to HH from the hospital or post-acute care (75%). On average, patients took 13 medications and had 9.2 diagnoses, with diabetes (31%), heart failure (30%), osteoarthritis (29%), chronic obstructive pulmonary disease (14%), aftercare for joint replacement (14%), and cancer (10%) being the most common. Patients reported prevalent depression (44%) and had a total of 4.1 ADL dependencies. The majority (83.4%) received daily informal caregiver support with ADLs. Over one fifth of the patients ( $n = 1,340$ , 21.8%) had severe pain, and nearly one quarter ( $n = 1,525$ , 24.8%) had ADRD. Significant differences were noted between patients in different pain and ADRD cohorts. Detailed sample characteristics are presented in Table 1.

Patients with ADRD were less likely to have recorded severe pain than others (16.4% vs. 23.6%,  $p < .001$ ). For patients with a diagnosis of ADRD, as the level of cognitive impairment (M1700) increased, the rate of reported severe pain decreased ( $p < .05$ ; see Table 2 and Fig. 1). In the multivariate logistic regression model that adjusted for covariates, having ADRD was related to a 28% lower

likelihood (odds ratio = 0.72, 95% confidence interval [CI]: 0.61, 0.86;  $p < .0001$ ) of having recorded severe pain (Table 3).

Severe pain has a statistically significant independent positive effect on risk of unplanned facility admission in HH recipients, but this effect was not significantly different for patients with ADRD than for those without. In the multivariate Cox proportional hazard model of unplanned facility admission adjusting for the above covariates, having severe pain was related to a 35% increase (hazard ratio [HR] = 1.35, 95% CI: 1.17, 1.64;  $p = .002$ ) in risk of unplanned facility admissions (Table 4). The interaction between pain and ADRD was not significantly related to the risk of facility admission (HR = 0.83, 95% CI: 0.57, 1.20;  $p = .33$  [Table 4]). We examined the linear combination of coefficients of pain and the interaction term (pain\*ADRD) and found that pain was related to 35% increased risk of unplanned facility admission in patients without ADRD (combined coefficient = 0.30, HR =  $e^{(0.30)} = 1.35$ ,  $p = .002$ ), but was not significantly related to the risk of facility admission in patients with ADRD (combined coefficient = 0.11, HR =  $e^{(0.11)} = 1.12$ ,  $p = .49$ ).

## Discussion

This was the first study that examined the association between ADRD status and severe, interfering pain among Medicare HH recipients, and the impact of severe pain on facility admissions in the context of HH care. The findings partially supported our hypotheses. First, older Medicare HH patients with ADRD were less likely to have recorded severe pain than those without ADRD. Second, having severe pain significantly increased the risk of having unplanned admission to the hospital, skilled nursing facilities or rehabilitation facilities among Medicare HH recipients. However, we did not find significant interaction between pain and ADRD. The effect of pain on risk of unplanned facility admission was significant only among patients without ADRD, but not significant among those with ADRD.

The finding that ADRD patients had a lower rate of recorded severe pain suggests that pain may be under-reported in these patients. This claim is consistent with existing literature reporting that pain in the nursing home and the hospital is not consistently recognized or documented among patients with cognitive impairment (Ferrell et al., 1995; Paulson et al., 2014; Sengstaken & King, 1993; Wu et al., 2005).

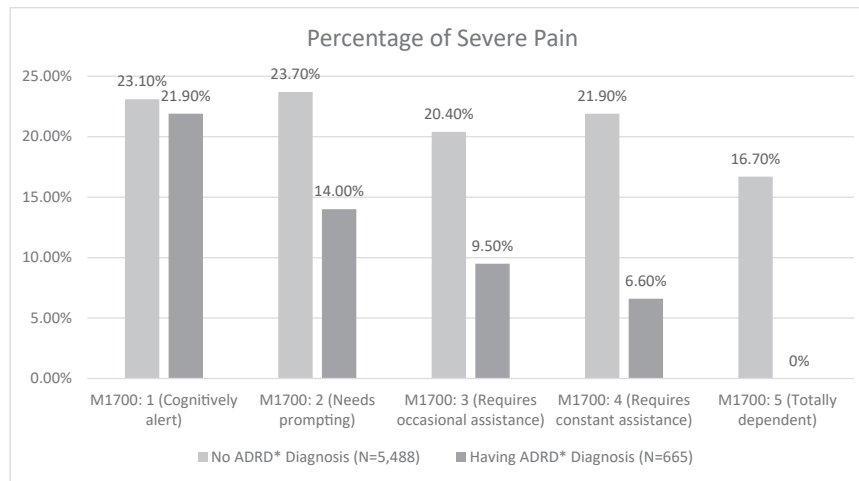
The lower recorded rate of severe pain in HH recipients with ADRD has several possible explanations, some of which involve the three sources of data for pain assessment in the OASIS, i.e., patient self-report, proxy report, and clinician observation. First, when compared with patients with intact cognition, patients with ADRD,

**Table 2**  
Relationship Between Cognitive Functioning and Severe Pain

Cognitive Functioning (M1700)	Severe Pain, %, (N)		Total
	No ADRD Diagnosis (5,488)	Having ADRD Diagnosis (665)	
1: Alert/oriented, able to focus and shift attention, comprehends and recalls task directions independently.	23.1% (484)	21.9% (7)	23.08% (491)
2: Requires prompting (cuing, repetition, reminders) only under stressful or unfamiliar conditions.	23.7% (665)	14.0% (33)	22.94% (698)
3: Requires assistance and some direction in specific situations (for example, on all tasks involving shifting of attention) or consistently requires low-stimulus environment due to distractibility.	20.4% (105)	9.5% (22)	16.98% (127)
4: Requires considerable assistance in routine situations. Is not alert and oriented, or is unable to shift attention and recall directions more than half the time.	21.9% (14)	6.6% (9)	11.44% (23)
5: Totally dependent due to disturbances such as constant disorientation, coma, persistent vegetative state, or delirium.	16.7% (1)	0% (0)	2.94% (1)
<i>p</i> value*	.568	.011	<0.0001

ADRD = Alzheimer's disease and Related Dementia.

\* *p* value of chi square tests.



**Figure 1.** Percentage of severe pain in different Alzheimer's disease and related dementia (ADRD) diagnosis and cognitive functioning groups.

particularly those who are noncommunicative, are less capable of recognizing pain (Corbett et al., 2012) and less likely to report pain owing to their potentially higher pain tolerance (Monroe et al., 2016). Although ADRD impairs one's cognitive function (Corbett et al., 2012), many with mild to moderate ADRD and relatively reserved cognitive function retain the ability to reliably report pain (Herr, 2011; Wang et al., 2017). Clinicians working with persons with ADRD should therefore try to obtain self-report data of pain early in the course of care and to ensure that both verbal and

behavioral signs of pain are correctly noted and documented (Monroe & Mion, 2012). In patients with severe dementia and limited ability to communicate, an observational pain tool should be attempted (Herr, 2011).

Second, caregivers may not have the skills necessary to identify pain in someone with ADRD. In a national survey with 2,089 family caregivers of patients with chronic illness or disability, approximately three quarters of the participants reported that they are constantly providing, and struggling with, complex medical care tasks such as

**Table 3**  
Correlates of Severe Pain

Severe Pain	Odds Ratio	95% Confidence Interval		p Value
Alzheimer's disease and related dementias	0.722	0.605	0.862	<.001
Age	0.972	0.964	0.980	<.001
Female	1.229	1.069	1.413	.004
Married	0.926	0.791	1.084	.337
Race/ethnicity (reference: non-Hispanic White)				
Black	0.893	0.715	1.113	.314
Hispanic	1.270	0.789	2.045	.325
Other (e.g., Asian)	0.713	0.381	1.335	.290
Living arrangements (reference: living with others at home)				
Live alone	1.009	0.843	1.208	.924
Aggregate settings	0.681	0.520	0.890	.005
Medicare-Medicaid dual eligibility	1.084	0.717	1.638	.703
Referral source (reference: community)				
Following acute hospitalization or post-acute care	0.834	0.708	0.983	.030
Number of diagnoses	0.981	0.959	1.004	.097
Number of medications	1.050	1.036	1.063	<.001
Heart Failure	0.874	0.727	1.051	.152
COPD	0.841	0.697	1.015	.070
Diabetes	0.805	0.689	0.939	.006
Osteoarthritis	1.325	1.147	1.530	<.001
Joint replacement	2.201	1.811	2.677	<.001
Cancer	0.901	0.713	1.138	.381
Current smoking	0.773	0.643	0.930	.006
Exhaustion	0.968	0.842	1.112	.644
Obesity	1.090	0.933	1.272	.278
Depression	1.035	0.901	1.188	.629
Composite ADL limitation score	1.309	1.234	1.388	<.001
Having daily caregiver assistance with ADL	0.913	0.747	1.117	.376
Days of index home health admission	0.999	0.997	1.000	.147
Intensity of HH services				
Skilled nursing (visits/week)	0.954	0.914	0.995	.029
Physical therapy (visits/week)	1.132	1.068	1.200	<.001
Occupational therapy (visits/week)	0.941	0.839	1.056	.303
Social work (yes/no)	1.274	1.000	1.624	.050
Aide assistance (yes/no)	1.064	0.850	1.331	.591

ADL = activities of daily living; HH = home health; COPD = chronic obstructive pulmonary disease.



**Table 4**

Multivariate Cox Proportional Model on the Relationship of Severe Pain and Alzheimer's Disease and Related Dementias (ADRD) with Unplanned Facility Admissions\*

Unplanned Facility Admission	Hazard Ratio	95% Confidence Interval		p Value
Severe pain	1.352	1.117	1.636	.002
ADRD	1.165	0.975	1.394	.093
Severe pain ADRD*	0.829	0.571	1.204	.325
Age	1.002	0.994	1.011	.600
Female	0.833	0.725	0.957	.010
Married	0.947	0.805	1.115	.514
Race/ethnicity (reference: non-Hispanic White)				
Black	0.684	0.547	0.855	.001
Hispanic	0.922	0.565	1.506	.746
Others (e.g., Asian)	0.651	0.344	1.232	.187
Living arrangements (reference: living with others at home)				
Live alone	1.086	0.902	1.308	.386
Aggregate settings	1.336	1.057	1.689	.015
Medicare-Medicaid dual eligibility	1.476	1.004	2.168	.048
Referral source (reference: community)				
After acute hospitalization or post-acute care	1.499	1.266	1.775	<.001
Number of diagnoses	1.068	1.043	1.093	<.001
Number of medications	1.000	0.987	1.012	.969
Heart failure	1.548	1.324	1.810	<.001
COPD	1.081	0.916	1.276	.359
Diabetes	0.902	0.775	1.051	.186
Osteoarthritis	0.771	0.658	0.904	.001
Joint replacement	0.377	0.238	0.599	<.001
Cancer	1.742	1.451	2.092	<.001
Current smoking	0.908	0.766	1.077	.268
Exhaustion	1.125	0.965	1.311	.134
Obesity	0.925	0.783	1.092	.358
Depression	0.964	0.838	1.109	.606
Composite ADL limitation score	1.138	1.075	1.206	<.001
Having daily caregiver assistance with ADL	1.052	0.847	1.306	.649
Skilled nursing (reference: quartile 1 [mean 0.26 visits/week])				
Quartile 2 (mean 1.02)	1.210	1.000	1.462	.050
Quartile 3 (mean 1.59)	0.955	0.781	1.168	.653
Quartile 4 (mean 3.30)	0.633	0.495	0.808	<.001
Physical therapy (reference: quartile 1 [mean 0.01 visits/week])				
Quartile 2 (mean 0.57)	1.266	1.061	1.511	.009
Quartile 3 (mean 1.41)	0.653	0.528	0.808	<.001
Quartile 4 (mean 2.46)	0.175	0.121	0.251	<.001
Occupational therapy (reference: quartile 1 [mean 0 visits/week]; quartile 2 omitted [mean 0])				
Quartile 3 (mean 0.21)	1.173	0.978	1.407	0.086
Quartile 4 (mean 0.94)	0.912	0.762	1.092	0.316
Receiving any social work services (yes/no)	0.752	0.598	0.945	0.015
Receiving any aide assistance (yes/no)	0.860	0.697	1.060	0.156

ADL = activities of daily living; ADRD = Alzheimer's disease and Related Dementia; COPD = chronic obstructive pulmonary disease.

\* Model controlled for time varying effects of HH intensity variables (i.e., skilled nursing visits per week, physical therapy visits per week, and receiving any aide assistance).

those related to pain assessment and management without much training and support from the medical care team (Reinhard, 2019).

Third, HH clinicians may not be adequately trained to assess and manage pain. Although previous literature has shown that geriatric-trained advanced-practice nurses and physicians appear better at prescribing appropriate medications to older adults (Monroe et al., 2011), they may lack tailored education and training in pain assessment in the context of ADRD. Nurses are at the frontline of providing HH care, yet they report continued difficulty in assessing and managing pain in people with ADRD (Gilmore-Bykovskiy & Bowers, 2013; Monroe et al., 2015), with noted deficits in knowledge and preparedness in doing so (Glajchen & Bookbinder, 2001). Moreover, pain assessment in OASIS does not include protocols that help HH clinicians identify nonverbal signs and behaviors that suggest pain in noncommunicative patients with ADRD.

Challenges in pain assessment are ubiquitous in HH care and are not limited to patients with cognitive impairment. The pain assessment items in OASIS have high reliability (i.e., Cohen's  $k = 0.61$ – $0.74$ ), but the accuracy rate was only 54.3% (Madigan & Fortinsky, 2001; Madigan et al., 2003). The detection of pain in OASIS primarily relies on HH clinicians' competency in recognizing

pain and conditions that may cause pain, which vary across disciplines given their education and training (Madigan et al., 2003). Even among disciplines that have a traditional emphasis on pain-assessment training, such as nursing, HH clinicians reported frustration in assessing pain and administering effective pain management (Kee & Epps, 2001). It is therefore important to offer training on the accurate identification of pain across all HH disciplines.

Since January 2020, the CMS (2019b) has removed the measure of "Pain Interventions Implemented During All Episodes" from the on-demand tally reports (a process used by CMS to assess the quality of reporting in HH care). Studies with national data about HH agencies in the United States showed that public reporting of pain improved pain control (Jung et al., 2010). Not requiring public report of pain interventions may thus affect the implementation of these interventions in HH. Future monitoring is required to ensure that pain of all patients is recognized and that effective measures are taken to reduce the severity and impact of pain (Monroe et al., 2015).

The finding that severe pain is related to increased risk of unplanned facility admissions is consistent with prior work in non-HH settings showing that patients with pain often have

unfavorable health outcomes, as stated previously. It is intriguing, however, that the impact of reported pain on unplanned facility admission was significant only among patients without ADRD, not among patients with ADRD. Perhaps patients without ADRD were more able and likely to report their pain and concern about underlying medical conditions to their medical providers, and for some cases, these underlying conditions necessitated admission to facilities for further investigation and intensive pain management. Conversely, this finding also raises the possibility that pain may be under-recognized in patients with cognitive impairment (Table 2; Fig. 1), and those who had pain did not receive enough medical attention.

Several studies have noted the positive effects of HH-based interventions on increasing HH clinicians' knowledge of pain management (Brody et al., 2016) and on improving pain-related outcomes in patients without ADRD (Bach et al., 2013; Egnatios, 2015). Perhaps what was lacking was focused attention to pain in the context of ADRD. HH clinicians do not have the training or skills necessary to adequately detect and manage pain in patients who have cognitive impairment and are not communicative. Potential solutions include: (1) engaging HH aides in assessing pain, because they spend the most time with the patients and thus could be attentive to changes in the patient's behaviors that suggest pain; and (2) providing support for family caregivers of patients with ADRD on early recognition and management of pain.

### Strengths and Limitations

This is the first study to examine the relationship of recorded pain with ADRD status and the impact of severe pain on facility admissions in Medicare HH recipients. The study has limitations. First, the data used in this study were from one HH agency in New York. This agency serves patients from seven counties in both urban and rural regions, and, as compared to the national HH population, has similar demographic characteristics (mean age 80.1 vs. 79.4, female 58% vs. 60.9%, non-Hispanic white 79.9% vs. 76.1%) except for a lower rate of Medicaid eligibility (2% vs. 9.5–12%; Harris-Kojetin et al., 2019). Second, Medicare claims and OASIS data include limited information about the severity of dementia. Third, our findings may be biased due to uncontrolled confounders, such as the use of analgesics and nonpharmacological interventions. However, the detailed patient information available in the OASIS assessment data that we used in our analyses should help mitigate this concern.

### Implications for Nursing Education, Practice, and Research

Untreated pain in older adults with ADRD is a critical public health concern (Monroe & Mion, 2012). Nurses comprise the largest body of healthcare providers in HH (Harris-Kojetin, 2019). Those who have prior training in pain assessment and management should take the lead in advocating accurate pain assessment and implementing effective treatment and interventions for pain in HH patients. Training, protocols, and resources should be made available to HH nurses for improved assessment and management of pain. Disseminating validated brief pain assessment scales targeted at patients with ADRD (e.g., the Pain Assessment in Advanced Dementia Scale, reviewed in Herr, [2011] in HH settings may be a reasonable first step.

### Conclusion

Older Medicare HH patients with ADRD were more likely to have unrecognized pain. Having severe, interfering pain was associated with a significant increase in the risk of unplanned facility

admissions. Systematic protocols and policy guidelines should be available to facilitate pain assessment for improved quality of care and health outcomes in HH patients with cognitive impairment.

### References

- Bach, E., Beissner, K., Murtaugh, C., Trachtenberg, M., & Reid, M. C. (2013). Implementing a cognitive-behavioral pain self-management program in home health care, part 2: Feasibility and acceptability cohort study. *Journal of Geriatric Physical Therapy*, 36(3), 130–137.
- Brody, A. A., Guan, C., Cortes, T., & Galvin, J. E. (2016). Development and testing of the Dementia symptom management at home (DSM-H) program: An inter-professional home health care intervention to improve the quality of life for persons with dementia and their caregivers. *Geriatric Nursing*, 37(3), 200–206.
- Centers for Medicare & Medicaid Services (CMS). (2019a). Home Health Compare: Quality measures. Retrieved from <https://www.medicare.gov/homehealthcompare/About/Quality-Measures.html>. (Accessed 12 May 2020).
- Center for Medicare and Medicaid Services (CMS). (2019b). Spotlight and Announcements. Retrieved from <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/HomeHealthQualityInits/Spotlight-and-Announcements>. (Accessed 12 May 2020).
- Corbett, A., Husebo, B., Malcangio, M., Staniland, A., Cohen-Mansfield, J., Aarsland, D., & Ballard, C. (2012). Assessment and treatment of pain in people with dementia. *Nature Reviews Neurology*, 8(5), 264–274.
- Dobscha, S. K., Corson, K., Pruitt, S., Crutchfield, M., & Gerrity, M. S. (2006). Measuring depression and pain with home health monitors. *Telemedicine Journal and E-Health*, 12(6), 702–706.
- Egnatios, D. (2015). Improving pain outcomes in home health patients through implementation of an evidence-based guideline bundle. *Home Healthcare Now*, 33(2), 70–78.
- Ferrell, B. A., Ferrell, B. R., & Rivera, L. (1995). Pain in cognitively impaired nursing home patients. *Journal of Pain and Symptom Management*, 10(8), 591–598.
- Gilmore-Bykovskiy, A. L., & Bowers, B. J. (2013). Understanding nurses' decisions to treat pain in nursing home residents with dementia. *Research in Gerontological Nursing*, 6(2), 127–138.
- Glajchen, M., & Bookbinder, M. (2001). Knowledge and perceived competence of home care nurses in pain management: A national survey. *Journal of Pain and Symptom Management*, 21(4), 307–316.
- Harris-Kojetin, L., Sengupta, M., Park-Lee, E., Valverde, P., Caffery, C., Rome, V., & Lendon, J. (2016). Long-term care providers and services users in the United States: Data from the National Study of Long-Term Care Providers, 2013–2014. *Vital Health Stat*, 3(38), x–xii, 1–105.
- Harris-Kojetin, L. S. M., Lendon, J. P., Rome, V., Valverde, R., & Caffery, C. (2019). Long-term care providers and services users in the United States, 2015–2016. Retrieved from [https://www.cdc.gov/nchs/data/series/sr\\_03/sr03\\_43-508.pdf](https://www.cdc.gov/nchs/data/series/sr_03/sr03_43-508.pdf). (Accessed 12 May 2020).
- Harrison, K. L., Ritchie, C. S., Patel, K., Hunt, L. J., Covinsky, K. E., Yaffe, K., & Smith, A. K. (2019). Care settings and clinical characteristics of older adults with moderately severe dementia. *Journal of the American Geriatrics Society*, 67(9), 1907–1912.
- Herr, K. (2011). Pain assessment strategies in older patients. *Journal of Pain*, 12(3 Suppl 1), S3–S13.
- Husebo, B. S., Achterberg, W., & Flo, E. (2016). Identifying and managing pain in people with Alzheimer's disease and other types of dementia: A systematic review. *CNS drugs*, 30(6), 481–497.
- Jung, K., Shea, D., & Warner, C. (2010). Agency characteristics and changes in home health quality after Home Health Compare. *Journal of Aging and Health*, 22(4), 454–476.
- Kang, Y., McHugh, M. D., Chittams, J., & Bowles, K. H. (2017). Risk factors for all-cause rehospitalization among Medicare recipients with heart failure receiving telehomecare. *Telemedicine Journal and E-Health*, 23(4), 305–312.
- Kee, C. C., & Epps, C. D. (2001). Pain management practices of nurses caring for older patients with osteoarthritis. *Western Journal of Nursing Research*, 23(2), 195–210.
- Lohman, M. C., Scherer, E. A., Whiteman, K. L., Greenberg, R. L., & Bruce, M. L. (2017). Factors associated with accelerated hospitalization and re-hospitalization among Medicare home health patients. *The Journals of Gerontology: Series A*, glw335.
- Madigan, E. A., & Fortinsky, R. H. (2001). Additional psychometric evaluation of the Outcomes and Assessment Information Set (OASIS). *Home Health Care Services Quarterly*, 18(4), 49–62.
- Madigan, E. A., Gordon, N., Fortinsky, R. H., Koroukian, S. M., Piña, I., & Riggs, J. S. (2012). Predictors of functional capacity changes in a U.S. population of Medicare home health care patients with heart failure. *Archives of Gerontology and Geriatrics*, 54(3), e300–e306.
- Madigan, E. A., Tullai-McGuinness, S., & Fortinsky, R. H. (2003). Accuracy in the Outcomes and Assessment Information Set (OASIS): Results of a video simulation. *Research in Nursing and Health*, 26(4), 273–283.
- Malara, A., De Biase, G. A., Bettarini, F., Ceravolo, F., Di Cello, S., Garo, M., Praino, F., Settembrini, V., Sgro, G., Spadea, F., & Rispoli, V. (2016). Pain assessment in elderly with behavioral and psychological symptoms of dementia. *Journal of Alzheimer's Disease*, 50, 1217–1225.

- Medicare Payment Advisory Commission. (2019). Report to the Congress: Medicare payment policy. Washington, DC. Retrieved from <http://www.medpac.gov/-research-areas-/post-acute-care>. (Accessed 12 May 2020).
- Monroe, T., Carter, M., & Parish, A. (2011). A case study using the Beers list criteria to compare prescribing by family practitioners and geriatric specialists in a rural nursing home. *Geriatric Nursing*, 32(5), 350–356.
- Monroe, T. B., Beach, P. A., Bruehl, S. P., Dietrich, M. S., Rogers, B. P., Gore, J. C., Atalla, S. W., & Cowan, R. L. (2017). The impact of Alzheimer's disease on the resting state functional connectivity of brain regions modulating pain: A cross-sectional study. *Journal of Alzheimer's Disease*, 57(1), 71–83.
- Monroe, T. B., Gibson, S. J., Bruehl, S. P., Gore, J. C., Dietrich, M. S., Newhouse, P., Atalla, S., & Cowan, R. L. (2016). Contact heat sensitivity and reports of unpleasantness in communicative people with mild to moderate cognitive impairment in Alzheimer's disease: A cross-sectional study. *BMC Medicine*, 14(1), 1–9.
- Monroe, T. B., & Mion, L. C. (2012). Patients with advanced dementia: How do we know if they are in pain? *Geriatric Nursing*, 33(3), 226–228.
- Monroe, T. B., Misra, S., Habermann, R. C., Dietrich, M. S., Bruehl, S. P., Cowan, R. L., Newhouse, P. A., & Simmons, S. F. (2015). Specific physician orders improve pain detection and pain reports in nursing home residents: Preliminary data. *Pain Management Nursing*, 16(5), 770–780.
- Monroe, T. B., Misra, S. K., Habermann, R. C., Dietrich, M. S., Cowan, R. L., & Simmons, S. F. (2014). Pain reports and pain medication treatment in nursing home residents with and without dementia. *Geriatrics & Gerontology International*, 14(3), 541–548.
- Monroe, T. B., Parish, A., & Mion, L. C. (2015). Decision factors nurses use to assess pain in nursing home residents with dementia. *Archives of Psychiatric Nursing*, 29(5), 316–320.
- O'Connor, M., & Davitt, J. K. (2012). The Outcome and Assessment Information Set (OASIS): A review of validity and reliability. *Home Health Care Services Quarterly*, 31(4), 267–301.
- O'Sullivan, K., Kennedy, N., Purtill, H., & Hannigan, A. (2016). Understanding pain among older persons: Part 1—the development of novel pain profiles and their association with disability and quality of life. *Age and Ageing*, 46(1), 46–51.
- Paulson, C. M., Monroe, T., & Mion, L. C. (2014). Pain assessment in hospitalized older adults with dementia and delirium. *Journal of Gerontological Nursing*, 40(6), 10–15.
- Reinhard, S. (2019). Home alone revisited: Family caregivers providing complex care. *Innovation in Aging*, 3(Suppl 1), S747.
- Sengstaken, E. A., & King, S. A. (1993). The problems of pain and its detection among geriatric nursing home residents. *Journal of the American Geriatrics Society*, 41(5), 541–544.
- Smith, D., Wilkie, R., Croft, P., & McBeth, J. (2018). Pain and mortality in older adults: The influence of pain phenotype. *Arthritis Care & Research*, 70(2), 236–243.
- Smith, P. D., Becker, K., Roberts, L., Walker, J., & Szanton, S. L. (2016). Associations among pain, depression, and functional limitation in low-income, home-dwelling older adults: An analysis of baseline data from CAPABLE. *Geriatric Nursing*, 37(5), 348–352.
- Smith, P. D., Boyd, C., Bellantoni, J., Roth, J., Becker, K. L., Savage, J., Nkimbeng, M., & Szanton, S. L. (2016). Communication between office-based primary care providers and nurses working within patients' homes: an analysis of process data from CAPABLE. *Journal of Clinical Nursing*, 25(3–4), 454–462.
- Wang, J., Caprio, T. V., Simning, A., Shang, J., Conwell, Y., Yu, F., & Li, Y. (2019). Association between home health services and facility admission in older adults with and without Alzheimer's disease and related dementias. *The Journal of Post-Acute and Long-Term Care Medicine*.
- Wang, J., Dietrich, M. S., Simmons, S. F., Cowan, R. L., & Monroe, T. B. (2017). Pain interference and depressive symptoms in communicative people with Alzheimer's disease: A pilot study. *Aging & Mental Health*, 1–5.
- Wang, J., Liebel, D. V., Yu, F., Caprio, T. V., & Shang, J. (2018). Inverse dose-response relationship between home health care services and rehospitalization in older adults. *Journal of the American Medical Directors Association*, 20(6), 736–742.
- Wu, N., Susan, C. M., Kate, L., Roy, J., & Mor, V. (2005). Impact of cognitive function on assessments of nursing home residents' pain. *Medical Care*, 43(9), 934–939.