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Pain and Emergency Department Use in the Last Month of Life Among Older Adults With Dementia



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Abstract

Context. Pain may be a potentially modifiable risk factor for expensive and burdensome emergency department (ED) visits near the end of life for older adults with dementia.

Objectives. The objective of this study was to assess the effect of pain and unmet need for pain management on ED visits in the last month of life in older adults with dementia.

Methods. This is a mortality follow-back study of older adults with dementia in the National Health and Aging Trends Study who died between 2012 and 2014, linked to Medicare claims.

Results. Two hundred eighty-one National Health and Aging Trends Study decedents with dementia met criteria (mean age 86 years, 61% female, 81% white). Fifty-seven percent had at least one ED visit in the last month of life, and 46.5% had an ED visit that resulted in a hospital admission. Almost three out of four (73%) of decedents experienced pain in the last month of life, and 10% had an unmet need for pain management. After adjustment for age, gender, race, educational attainment, income, comorbidities, and impairment in activities of daily living, pain was not associated with increased ED use in the last month of life (adjusted incident rate ratio 0.87, 95% CI 0.64–1.17). However, decedents with unmet need for pain management had an almost 50% higher rate of ED visits in the last month of life than those without unmet needs (adjusted incident rate ratio 1.46, 95% CI 1.07–1.99).

Conclusion. Among older adults with dementia, unmet need for pain management was associated with more frequent ED visits in the last month of life. *J Pain Symptom Manage* 2018;56:871–877. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine.

Key Words

Dementia, end-of-life, emergency department, pain

Introduction

Owing to population aging and a lack of curative treatments, the number of older adults with dementia in the U.S. is growing rapidly. Currently, more than 5 million adults over the age of 65 years in the U.S. have dementia. This number will expand to 13.8 million by 2050 in the absence of effective treatment.¹ Given

estimates that one-third of all decedents over the age of 65 years die either with or from dementia, improving the quality of care at the end of life for persons with dementia is a national priority.^{2,3}

Emergency department (ED) use by older adults increases dramatically near the end of life.^{4,5} Some of these visits may be potentially avoidable with improved access to both primary and palliative care.⁶ Major

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health policy initiatives now include mandates for the reduction of potentially avoidable ED visits and hospital admissions by older adults with dementia as part of efforts to improve care quality and value.^{3,7} Achieving these reductions requires targeting and tailoring interventions to older adults with dementia at highest risk for increased utilization. However, knowledge of patterns of ED use and risk factors associated with higher ED utilization in older adults with dementia at the end of life is limited.

Pain may be one potentially modifiable risk factor for increased ED visits for older adults with dementia at end of life. The clinical course of dementia is notable for increasing pain near the end of life.⁸ Pain in older adults with dementia commonly manifests as behavioral symptoms, such as agitation, that caregivers often find very challenging to manage.⁹ Overwhelmed caregivers may panic in response to their loved one's distress and see the ED as the only means of obtaining treatment, especially outside of regular office hours.¹⁰

However, little is currently known specifically about the relationship between pain and ED use at the end of life for older adults with dementia. Thus, the objectives of this study were to 1) assess prevalence of pain and unmet need for pain management in the last month of life in older adults dying with dementia; 2) describe ED use in the last month of life among older adults with dementia; and 3) examine whether pain was associated with increased ED use in the last month of life in older adults with dementia.

Methods

Population and Setting

The National Health and Aging Trends Study (NHATS) is a prospective panel study designed to increase knowledge on trends in late-life functioning of older adults in the U.S. Begun in 2011, NHATS draws from a nationally representative sampling frame of adults aged 65 years and older in the U.S. and includes oversamples of non-Hispanic black persons and older adults (≥ 90).^{11,12} NHATS assessments are performed annually in-person in the participant's place of residence and include verbal questionnaires, performance-based metrics of cognitive and physical functioning, and facility assessments if applicable. Proxy respondents are interviewed if participants are unable to respond for themselves. In addition, NHATS includes a mortality follow-back survey (last month of life interview) completed by proxy respondents, which includes questions about type and quality of care NHATS participants received in the last month of life.

We selected all NHATS participants with a complete interview in 2011 who died between 2012 and 2014

and had a last month of life interview completed by a proxy familiar with the decedent. We linked data for NHATS decedents with the Center for Medicare and Medicaid Files, including the Medicare Beneficiary Summary File and Medicare Part A and B claims files. Participants who did not have continuous Medicare fee-for-service Part A and B enrollment in the last two months of life were excluded because it was not possible to assess individual level health care use for these individuals.

Dementia Ascertainment

Decedent's dementia status was determined using a previously defined and validated algorithm.¹³ Briefly, this algorithm is based on 1) self-report or proxy report of a physician's diagnosis of dementia; 2) scoring on cognitive testing in three domains (orientation, memory, and executive function); and 3) AD8 score for those with a proxy respondent (eight-item measure designed for administration to informants for the purpose of identifying the presence of dementia).^{14,15} NHATS participants are classified as no dementia, possible dementia, and probable dementia. Sensitivity and specificity of this approach for identifying probable dementia are 65.7% and 87.2%, respectively.¹³ We assigned dementia status based on results in the survey immediately before death (i.e., 2012 dementia status if participant died in 2013). The average number of days between the final survey completed by participants and their date of death was 186 days (SD 122 days). We defined our dementia cohort as including only participants with probable dementia. Participants whose dementia classification was missing in the survey before death were excluded.

Pain Assessment

Pain was assessed by asking proxy respondents who completed the NHATS last month of life interview questions regarding whether the decedent experienced pain in the last month of life, and if so, if they received the right amount of help in managing their pain. These questions were only asked about decedents who were alert as reported by proxies (i.e., awake and able to communicate at least some of the time) in the last month of life. We excluded decedents who had missing or do not know/refused response to any questions regarding pain. We created two dichotomous variables from these questions: 1) decedent experienced pain in the last month of life (yes/no) and 2) decedent had unmet need for pain management in the last month of life (yes/no) if they answered yes to experiencing pain and did not receive the right amount of help with pain management. This definition of unmet need for pain management is based on previous classifications in the literature.¹⁶

ED Visits

ED visit information was obtained from Medicare Part A and Part B claims. We assessed the percentage with and mean number of three types of ED visits: 1) any ED visit; 2) ED visit outpatient only and; 3) ED visit with a hospital admission. For each category of ED visit examined, we assessed whether decedents had a visit in the last month of life as well as the average number of visits. Using International Classification of Disease, Ninth Revision primary diagnosis codes, we assessed the top 10 most frequent diagnoses and rates per 100 persons in the last month of life for the any ED visit category. Online [Supplementary Table 2](#) includes the International Classification of Disease, Ninth Revision codes used to define diagnostic categories. Where there was crossover, we used the Charlson Comorbidity Index to guide category definition.¹⁷ Otherwise, we based categories on our clinical judgment.

Other Variables

Age at death was determined from the Medicare Beneficiary Summary File. Gender (male/female), race (white/black/Hispanic or other), and median income were extracted from the initial 2011 NHATS interview. Marital status (married or living with partner/widowed, divorced, separated, other) was assessed in the NHATS survey immediately preceding death. Residential care in the last month of life was determined from the NHATS last month of life interview. We defined residential care as including nursing homes, assisted living, board and cares, and other facilities that provide services to older adults. Activities of daily living (ADLs) were assessed in the NHATS survey immediately preceding death and included bathing, dressing, toileting, eating, transferring, going inside, and going outside. We defined ADL impairment (0/1 – 2/3 + impairments) as requiring assistance for the activity from another person. Comorbidities were assessed in the survey immediately preceding death and included a count of 10 conditions, including a history of heart attack, heart disease, high blood pressure, arthritis, osteoporosis, diabetes, lung disease, stroke, cancer, and broken hip. We assessed whether decedents received hospice services in the last month of life (yes/no) and, if so, hospice length of stay using Medicare claims files. A full description of variables included in our analysis is available in Online [Supplementary Table 1](#).

Statistical Analyses

Descriptive statistics were used to describe the sample characteristics and health care use. Using a Poisson regression, we examined the association between 1) pain and ED visit count in the last month of life

and 2) unmet need for pain management and any ED visit count (both outpatient only and with inpatient admission) in the last month of life. For each set of models, we present an unadjusted model, a model adjusted for age, gender, and race, and a model adjusted for age, gender, race, educational attainment, income, comorbidities, and ADL impairment. Incident rate ratio and 95% CIs were estimated for all models. All reported analyses, with the exception of ED visit diagnosis, were weighted for the differential probability of selection and took into account the complex survey design of NHATS. Weights from the survey immediately before death were used. Taylor linearization was used for variance estimation. Statistical analyses were conducted using Stata software, version 15 (Stata Corp., College Station, TX) and SAS software, version 9.4 (SAS Institute, Inc., Cary, NC). This study was approved by the University of California Institutional Review Board, the NHATS Data Confidentiality Committee, and Centers for Medicare & Medicaid Services Privacy Board.

Results

Between 2012 and 2014, 1081 NHATS participants died and had a complete last month of life interview, of whom 736 (68.1%) had fee-for-service Medicare Parts A and B in the last two months of life. We excluded 17 (2.3%) decedents who had dementia status missing in the interview before death, and 72 (9.8%) decedents who had missing data on pain in the last month of life, either because they were not alert or proxy respondents answered do not know or refused. Of the remaining 647 decedents, 291 were categorized as having dementia (38.8%). We excluded an additional 10 decedents because proxies were not familiar with their daily routines for a final sample of 281 decedents with dementia (Online [Supplementary Fig.1](#)).

Characteristics of the dementia decedent cohort are reported in [Table 1](#). The average age at death was 86.3 (± 7.8). The majority were female (61.3%), white (80.5%), high school graduates (50.5%), and just over one-third were married (36.3%). Median income was \$21,000. Just over one-third (36.6%) were living in residential care in the last month of life. Seventy percent of decedents had more than three ADL impairments in the survey before death and just over a half had four or more comorbidities (52.3%). Almost three-fourth of respondents reported that the decedent had pain in the last month of life (73.1%) and approximately 10% had an unmet need for pain management. More than half (56.6%) of decedents with dementia visited the ED in the last month of life. The mean number of ED visits was 0.75. Only a small

Table 1
**Characteristics of NHATS Decedents With Dementia
 2011–2014 (N = 281)**

Demographic	n (%) ^a
Age at death in years, mean (SD)	86.3 (7.8)
Female gender	174 (61.3)
Race	
White	186 (80.5)
Black	74 (10.2)
Hispanic/other	21 (9.3)
Education	
Less than high school diploma	125 (36.4)
High school graduate	119 (50.5)
Bachelor's or higher	37 (13.1)
Median income \$ (IQR)	21,000 (23,000)
Marital status	
Married or living with partner	85 (36.3)
Widowed/divorced/separated/never married	196 (63.7)
Living in residential care in the last month of life	86 (36.6)
Functional (ADL) impairments	
0	33 (11.9)
1–2	54 (18.4)
3+	194 (69.7)
Comorbidities	
0–1	35 (12.8)
2–3	98 (34.9)
4+	148 (52.3)
Pain	
Pain in the last month of life	203 (73.1)
Unmet need for pain management in the last month of life	28 (10.3)
ED visits	
Any ED visit	151 (56.6)
Any ED visit, mean (SD)	0.75 (0.76)
Outpatient-only ED visit	40 (14.4)
Outpatient-only ED visit, mean (SD)	0.17 (0.45)
ED visit with hospital admission	126 (46.5)
ED visit with hospital admission, mean (SD)	0.57 (0.68)
Hospice use	
Any hospice use	151 (50.7)
Hospice length of stay in days, mean (SD)	14.7 (11.9)

NHATS = National Health and Aging Trends Study; IQR = interquartile range; ADL = activities of daily living; ED = emergency department.

^aUnless otherwise noted.

proportion (14.4%) of decedents had outpatient-only ED visits that did not result in a hospital admission. About half (50.7%) received hospice during the last month of life, with a mean length of stay in hospice of 14.7 days.

There was no association between pain in the last month of life and ED visits (Table 2) (adjusted incident rate ratio 0.87, 95% CI 0.64–1.17). However, unmet need for pain management increased ED visit rate by almost 50% (adjusted incident rate ratio 1.46, 95% CI 1.07–1.99) after adjustment for age, gender, race, educational attainment, income, comorbidities, and ADL impairment. Fig. 1 shows the percentage of participants who had 0, 1, or 2+ ED visits by whether they had unmet need for pain management or not. A higher percentage of participants with unmet need for pain management had one (46% vs. 39%) or multiple ED visits (26% vs. 16%) compared to those without unmet need for pain management. The top

10 most frequent diagnoses for any ED visit were as follows: 1) septicemia; 2) cardiac arrest; 3) pneumonia and other respiratory disease; 4) malignancy; 5) congestive heart failure; 6) cerebrovascular disease; 7) cystitis and other urological infections; 8) hip and other bone fractures; 9) stomach/intestinal disorders; 10) fluid and electrolyte disturbances (Table 3).

Discussion

We found that almost three out of four of decedents with dementia experienced pain in the last month of life, the majority visited the ED at least once, and most of these ED visits resulted in a hospital admission. Although prevalence of unmet need for pain management was low (10%), it was associated with an almost 50% higher rate of ED visits in the last month of life than those without unmet need. While most frequent ED visit diagnoses were acutely painful, pain itself was not a top reason for ED visits. These findings suggest that persons with dementia in pain may be at increased risk for ED visits for other conditions, some of which may layer acute on chronic pain (e.g., fracture on osteoarthritis pain). Overall, our results point to a complex interplay between pain and declining health at the end of life and highlight the importance of the quality of pain management on ED use and subsequent hospitalizations at the end of life for older adults with dementia.

Our results suggest that interventions aimed at improving pain management for older adults with dementia at the end of life may aid in reducing ED visit rates and hospitalizations. Expanding access to hospice care for older adults with dementia, with its focus on pain and symptom management, may be one tactic for improving pain management and reducing ED use and hospitalizations at the end of life. Numerous studies have found that enrollment in and longer length of stay in hospice are associated with lower ED use and hospitalizations.^{4,18–20} However, although hospice use by persons with dementia has increased dramatically in the past 20 years,²¹ access is still limited. Only half of decedents with dementia in our study received hospice during the last month of life, and for most, this was only during the last two weeks of life.

Access to hospice for older adults with dementia is currently hindered by strict eligibility requirements for hospice based on prognosis, which is more difficult to determine in dementia compared to other terminal diseases.²² Loosening hospice eligibility criteria and changing payment mechanisms to reflect needs rather than prognosis is one potential strategy to addressing this issue.²³ Integrating consultative palliative care services into primary care, nursing home settings, and

Table 2
Unadjusted and Adjusted Incident Rate Ratio of Emergency Department (ED) Visits in the Last Month of Life in NHATS Decedents With Dementia by Pain Status (N = 281)

Pain Status	Mean Number of ED Visits in the Last Month of Life (SD)	Unadjusted IRR (95% CI)	Adjusted IRR ^a (95% CI)	Adjusted IRR ^b (95% CI)
Pain in the last month of life				
No	0.80 (0.77)	Reference	Reference	Reference
Yes	0.72 (0.75)	0.90 (0.64–1.25)	0.87 (0.64–1.17)	0.86 (0.63–1.17)
Unmet need for pain management in the last month of life				
No	0.71 (0.75)	Reference	Reference	Reference
Yes	1.02 (0.78)	1.42 (0.99–2.05)	1.48 (1.10–2.03) ^c	1.46 (1.07–1.99) ^c

NHATS = National Health and Aging Trends Study; IRR = incident rate ratio.

^aAdjusted for age, gender, race.

^bAdjusted for age, gender, race, educational attainment, income, comorbidities, and impairment in activities of daily living.

^cP < 0.05.

other models of care—such as home-based primary care—may also improve pain management and reduce ED use at the end of life for older adults with dementia.^{24–26} For example, early palliative care consults with nursing home residents with dementia were associated with an almost 12% reduction in ED visits in the last 30 days of life.²⁴ However, palliative care for people with dementia is in early stages of development, and more work is needed to develop palliative care models and programs tailored to the unique needs of people with dementia near the end of life.

ED-based interventions to reduce hospital admissions for older adults with dementia near the end of life may be another way to reduce the burdens on patients, families, and the health care system. The fact that we found that most ED visits resulted in a hospital admission underscores the high potential for possible

reductions in hospital admissions coming from the ED. Novel strategies, such as palliative care consults in the ED and ED rooms reserved for actively dying patients, are promising interventions that have been found to reduce hospital admissions and lengths of stay, ameliorate symptom burden, and increase care quality ratings by patients and families.^{27,28} However, avoiding ED visits in the first place through investment in community-based palliative care, hospice, and supportive models of care that can address pain, symptoms, and other palliative care needs still provides the most leverage for reducing hospital admissions in the last month of life.

Several limitations of this study are noted. The main limitation was the small sample size of individuals with unmet need for pain management. Although our findings did reach statistical significance for the effect of unmet need for pain management on ED use in the

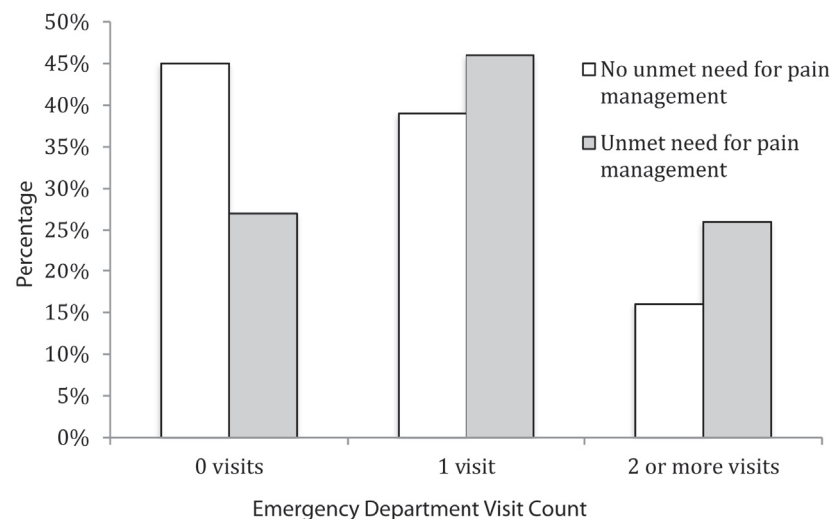


Fig. 1. Percentage of NHATS decedents with dementia (N = 281) with 0, 1, or 2+ emergency department visits in the last month by pain management status. NHATS = National Health and Aging Trends Study.

Table 3
Top 10 Primary Diagnoses and Rates for Any Emergency Department Visit in the Last Month of Life for NHATS Decedents With Dementia 2011–2014 (N = 281)

Rank	ICD-9 Primary Diagnosis	Rate per 100 Persons
1	Septicemia	6.4
2	Cardiac arrest	5.0
3	Pneumonia and other respiratory disease	4.3
4	Malignancy	4.0
5	Congestive heart failure	4.0
6	Cerebrovascular disease	3.6
7	Cystitis and other urological infections	2.9
8	Hip and other bone fractures	2.9
9	Stomach/intestinal disorders	2.5
10	Fluid and electrolyte disturbances	2.1

NHATS = National Health and Aging Trends Study, not adjusted for survey weights; ICD = International Classification of Disease.

adjusted model, this result should be interpreted with caution given the small sample size and the fact that Poisson regression tends to underestimate variance. However, these data provide important preliminary evidence and estimates of effect size that can inform future studies with larger sample sizes, which will become available with longer follow-up times for the NHATS cohort. Second, our study only included individuals with fee-for-service Medicare. Characteristics and health care patterns of older adults enrolled in Managed Medicare Organizations—which now comprise about one-third of all Medicare beneficiaries and are increasing—may differ.²⁹ Third, we cannot determine the direction of causality based on our data. Unmet need for pain management may prompt patients to seek relief for pain in the ED, but ED visits and hospitalizations could involve painful procedures or prolonged bed rest that may contribute to pain. Furthermore, because our study did not include a control group, we cannot compare our findings to populations without dementia. We opted to focus on a dementia-only cohort due to challenges in creating an accurately matched control group and because the assessment and treatment of pain in dementia varies substantially from those without dementia. Finally, pain assessment in the last month of life relied on retrospective report by proxy respondents. Although studies have demonstrated that proxies are able to reliably report pain on behalf of older adults with dementia,³⁰ there remains the possibility of proxy-response and recall bias.

In conclusion, addressing the needs of older adults with dementia at the end of life is a critical issue facing society today. Our findings show that ED use by older adults with dementia is very high in the last month of life, and most ED visits result in a hospital admission. While the presence of pain was not associated with increased ED use in decedents with dementia, preliminary results are strongly suggestive that unmet need

for pain management increases ED use. Despite limitations of sample size, our results indicate that improving pain management in older adults with dementia may result in reduced ED visits and hospital admissions in the last month of life. Enhancing access to hospice and palliative care for older adults with dementia is one potential strategy for achieving these patient-centered outcomes.

Disclosures and Acknowledgments

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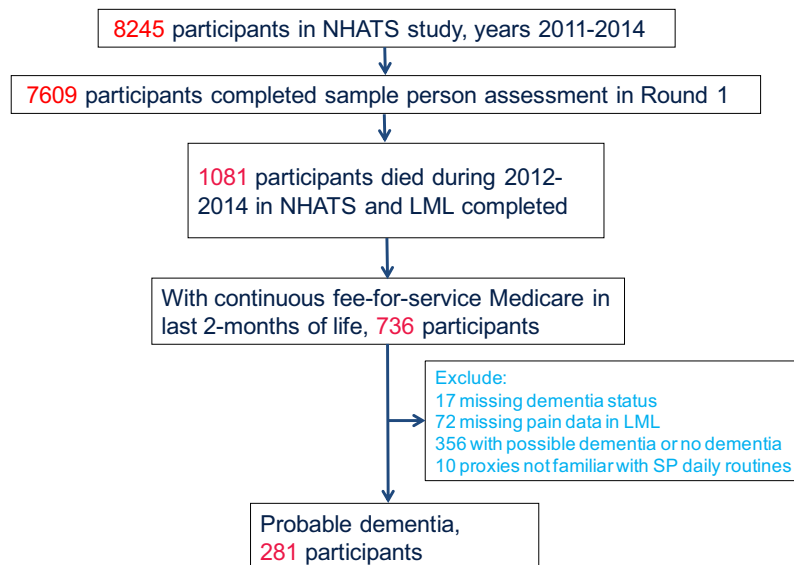
Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.jpainsymman.2018.09.005>.

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Supplementary Fig. 1. Flowchart of analytic cohort. LML = last month of life interview; NHATS = National Health and Aging Trends Study; SP = sample person.

Supplementary 2. Study Data Sources and Measurement Details

This supplement provides details on the data sources and measurement details used to construct variables for data analysis. Data sources for [Supplementary Table 1](#) include the National Health and Aging Trends Study (NHATS) surveys from Round 1 (2011), Round 2 (2012), Round 3 (2013), Round 4 (2014); the NHATS Last Month of Life Interview from Round 2 (2012), Round 3 (2013), and Round 4 (2014); the NHATS/Medicare Beneficiary Summary linked file; and NHATS/Medicare linked inpatient, outpatient, and Hospice claims files. In the NHATS survey, respondents include self-respondents, referred to as sample persons (SPs), and proxy respondents if sample persons are unable to respond for themselves. Last month of life interviews are completed by proxy respondents familiar with the sample person.

[Supplementary Table 2](#) provides the International Classification of Disease, Ninth Revision primary diagnosis codes used to define diagnostic categories for

assessing most frequent reasons for emergency department visits.

Note: NHATS has assisted secondary data analysts by providing a number of derived variables. Derived variables are created for variables with 1) complex skip patterns; 2) calculation of scores; and 3) SP file variables that combine information from prior and current rounds (if, e.g., the SP moved or had a change in marital status). Derived variables are indicated in variable naming with a “d” following the round year (e.g., r1dgender). See NHATS user guide for further information.¹

References

1. Kasper Judith D, Freedman Vicki A. National Health and Aging Trends Study User Guide: Rounds 1-6 Final Release. Baltimore: Johns Hopkins University School of Public Health, 2017. Available from https://www.nhats.org/scripts/documents/NHATS_User_Guide_R1_R6_2017_Revised_12_12_17.pdf. Accessed August 31, 2018.
2. Jill Montaquila, Freedman Vicki A, Kasper Judith D. National Health and Aging Trends Study Round 1 Income Imputation. Johns Hopkins University School of Public Health, 2012. Available from https://www.nhats.org/scripts/sampling/NHATS_Round1_Income_Imputation_11_09_12.pdf. Accessed August 31, 2018.

Supplementary Table 1
Data Source and Measurement Details of Characteristics and Outcomes of NHATS Decedents With Dementia

Characteristics and Outcomes	Data Source	Survey Question	Variable Name (if Applicable)	Operational Definition
Age at death	NHATS/Medicare Beneficiary Summary File	N/A	BENE_DEATH_DT	Continuous:
Gender	NHATS Round 1 Survey (2011)	{Are you/Is SP} male or female?	r1dgender (derived variable)	• Average age at death in years Dichotomous: • Male • Female
Race	NHATS Round 1 Survey (2011)	Do you consider yourself/Does SP consider {himself/herself} primarily 1) white/Caucasian; 2) black/African American; 3) American Indian; 4) Alaskan native; 5) Asian; 6) native Hawaiian; 7) Pacific Islander; 8) other; DK/RF {Do you/Does SP} consider {yourself/himself/herself} Hispanic or Latino? 1) Yes; 2) No	r1dracehisp (derived variable)	Categorical: • White = white, non-Hispanic • Black = black, non-Hispanic • Hispanic/other = other (Am Indian/Asian/native Hawaiian/Pacific Islander/other specify), non-Hispanic AND Hispanic AND DK/RF
Educational attainment	NHATS Round 1 Survey (2011)	What is the highest degree or level of school {you/SP} completed? 1) No schooling completed; 2) 1st–8th grade; 3) 9th–12th grade no diploma; 4) high school graduate (high school diploma or equivalent; 5) vocational, technical, business, or trade school certificate (beyond high school level); 6) some college but no degree; 7) associates degree; 8) bachelor's degree; 9) master's, professional, or doctoral degree; DK/RF	el1higstschl	Ordinal: • Less than high school: No schooling completed OR 1st–8th grade OR 9th–12th grade no diploma • High school graduate: High school graduate (high school diploma or equivalent AND vocational, technical, business, or trade school certificate (beyond high school level) AND some college but no degree AND associates degree; • Bachelor's or higher: bachelor's degree AND master's, professional, or doctoral degree
Income	NHATS Round 1 Survey (2011)	How much was {your/SP's}{and SP FIRSTNAME LASTNAME/SPOUSE/PARTNER FIRSTNAME LASTNAME}'s} total income before taxes for last year (this is, for the 12 months ending in December {CURRENT YEAR - 1})?	ia1totinc ia1totincim1-5: Imputed income if ia1totinc not completed. See NHATS Round 1 income imputation guide for more information. ²	Continuous: • Median income (\$)

(Continued)

Supplementary Table 1
Continued

Characteristics and Outcomes	Data Source	Survey Question	Variable Name (if Applicable)	Operational Definition
Marital status	NHATS Round Prior to Death (2011, 2012, 2013)	Round 1 2011: {Are you/Is SP} currently married, living with a partner, separated, divorced, widowed, or never married? 1) Married; 2) Living with partner; 3) Separated; 4) Divorced; 5) Widowed; 6) Never married; DK/RF Round 2 (2012) and Round 3 (2013): At the time of the last interview in {LAST INT MONTH AND YEAR}, {you were/SP was} {married/living with a partner/separated/divorced/widowed/never married}. Has that changed? That is, did {you/SP} get married, separated, divorced, remarried, widowed, or start living with a (different) partner 1) Yes; 2) No; DK/RF	Round 1 (2011): hh1martlstat Round 2 (2012) and 3 (2013): hh2dmarstat; hh3dmarstat (derived variable)	Dichotomous: • Married or living with partner: Married AND Living with partner • Widowed/divorced/separated/never married = Separated AND Divorced AND Widowed AND Never Married
Residential care	NHATS Last Month of Life (LML) Interview (2012, 2013, 2014)	Was this the kind of place that provides care, such as an assisted living facility, board and care home, nursing home, or other long-term care facility? 1) Yes; 2) No; DK/RF	Round 2 (2012): r2dresidlml (derived variable) Round 3 (2013): r3dresidlml (derived variable) Round 4 (2013): r4dresidlml (derived variable)	Dichotomous: • Living in residential care in LML • Not living in residential care in LML
Impairment in activities of daily living (ADL)	NHATS Round Prior to Death (2011, 2012, 2013)	Eating: In the last month, did anyone ever help {you/SP} eat, for instance, by cutting up food or feeding {you/{him/her}}? 1) Yes; 2) No; DK/RF Bathing: In the last month, did anyone ever help {you/SP} {shower/take a bath/wash up}? 1) Yes; 2) No; DK/RF Dressing: In the last month, did anyone ever help {you/SP} get dressed, for instance, by getting clothing over {your/{his/her}} head, helping with clothing behind {your/{his/her}} back like a belt {or bra}, or	Round 1 (2011): sc1deathelp Round 2 (2012): sc2deathelp Round 3 (2013): sc3deathelp Round 1 (2011): sc1dbathhelp Round 2 (2012): sc2dbathhelp Round 3 (2013): sc3dbathhelp Round 1 (2011): sc1dreshelp Round 2 (2012): sc2dreshelp Round 3 (2013): sc3dreshelp Round 1 (2011): sc1dtoilhelp Round 2 (2012): sc2dtoilhelp Round 3 (2013): sc3dtoilhelp Round 1 (2011): mo1dbedhelp Round 2 (2012): mo2dbedhelp Round 3 (2013): mo3dbedhelp	Ordinal: • 0 ADL impairments • 1–2 ADL impairments • 3 or more ADL impairments

Comorbidities	NHATS Round Prior to Death (2011, 2012, 2013)	helping {you/{him/her}}put on socks or shoes? 1) Yes; 2) No; DK/RF Toileting: In the last month, did anyone ever help {you/SP} use the toilet? 1) Yes; 2) No; DK/RF Transferring out of bed: In the last month {of {his/her}life}, did anyone ever help {you/SP} get out of bed? Going inside: In the last month, did anyone ever help {you/SP} get around inside {your/his/her} home {or building}? 1) Yes; 2) No; DK/RF Going outside: In the last month, did anyone ever help {you/SP} leave {your/his/her}{home/building}to go outside? 1) Yes; 2) No; DK/RF Round 1 (2011): I will read a list of some diseases and conditions that a doctor may have said {you have/SP has}. Please tell me if a doctor ever told {you/him/her} that {you/he/she} had 1) a heart attack or myocardial infarction; 2) any heart disease including angina or congestive heart failure; 3) high blood pressure or hypertension; 4) arthritis (including osteo or rheumatoid arthritis); 5) osteoporosis or thinning of the bones; 6) diabetes; 7) lung disease, such as emphysema, asthma, or chronic bronchitis; 8) a stroke; 9) dementia or Alzheimer's disease (*NOT INCLUDED IN OUR ANALYSIS*); 10) cancer. 1) Yes; 2) No; DK/RF Since age 50, has a doctor told {you/SP} that {you have/{he/she} has broken or fractured hip?	Round 1 (2011): mo1dinsdhelp Round 2 (2012): mo2dinsdhelp Round 3 (2013): mo3dinsdhelp All of the above are derived variables Round 1 (2011): mo1douthelp Round 2 (2012): mo2douthelp Round 3 (2013): mo3douthelp Note: all of the above variables are derived variables. Round 1 (2011): 1. history of heart attack (hc1disescn1) 2. heart disease (hc1disescn2) 3. high blood pressure (hc1disescn3) 4. arthritis (hc1disescn4) 5. osteoporosis (hc1disescn5) 6. diabetes (hc1disescn6) 7. lung disease (hc1disescn7) 8. stroke (hc1disescn8) 9. cancer (hc1disescn10) 10. broken hip (hc1brokebon1) Round 2 (2012): 1. history of heart attack (hc2disescn1) 2. heart disease (hc2disescn2) 3. high blood pressure (hc2disescn3) 4. arthritis (hc2disescn4) 5. osteoporosis (hc2disescn5) 6. diabetes (hc2disescn6) 7. lung disease (hc2disescn7) 8. stroke (hc2disescn8) 9. cancer (hc2disescn10)	Ordinal: • 0–1 comorbidities • 2–3 comorbidities • 4+ comorbidities
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(Continued)

Supplementary Table 1
Continued

Characteristics and Outcomes	Data Source	Survey Question	Variable Name (if Applicable)	Operational Definition
		1) Yes; 2) No; DK/RF In Rounds 2 and 3, wording changed as follows: We are interested in new health conditions that {you have/ SP has} learned about this year. Since the time of the last interview, has a doctor told {you/him/her} that {you/he/she} had (same list as above)?	10. broken hip (hc2brokebon1) Round 3: 1. history of heart attack (hc3disescn1) 2. heart disease (hc3disescn2) 3. high blood pressure (hc3disescn3) 4. arthritis (hc3disescn4) 5. osteoporosis (hc3disescn5) 6. diabetes (hc3disescn6) 7. lung disease (hc3disescn7) 8. stroke (hc3disescn8) 9. cancer (hc3disescn10) 10. broken hip (hc3brokebon1)	
Pain in the last month of life	NHATS LML Interview (2012, 2013, 2014)	During the last month of {SP}'s life, were there times when {he/she} experienced pain?	Round 2 (2012): lm2pain Round 3 (2013): lm3pain Round 4 (2014): lm4pain	Dichotomous: • Pain in the LML • No pain in the LML
Unmet need for pain management in the last month of life	NHATS LML Interview (2012, 2013, 2014)	1) Yes; 2) No; DK/RF Did {SP} get any help in dealing with {his/her} pain? 1) Yes; 2) No; DK/RF How much help in dealing with {his/her} pain did {SP} receive? 1) Less than was needed; 2) More than was needed; 3) About the right amount; DK/RF	Round 2 (2012): lm2painhlp Round 3 (2013): lm3painhlp Round 5 (2014): lm4painhlp Round 2 (2012): lm2painhlpam Round 3 (2013): lm3painhlpam Round 4 (2014): lm4painhlpam	Dichotomous: • Unmet need for pain management = No help OR Yes help but Help was less than was needed OR more than was needed • No unmet need for pain management = Yes help AND help was about the right amount
Any ED visit	NHATS/Medicare linked inpatient and outpatient claims files	N/A	NCH_CLM_TYPE_CD = 40, 60, 61 and Revenue Center Code 045X or 0981 or Healthcare Common Procedure Coding System (HCPCS) classification code 99281–99285	Dichotomous: • Any ED visit = yes/no Count: • Any ED visit average Ordinal (for Fig. 1): • 0 visits • 1 visit • 2 or more visits
Outpatient-only ED visit	NHATS/Medicare linked outpatient claims files	N/A	NCH_CLM_TYPE_CD = 40, and Revenue Center Code 045X or 0981 OR Healthcare Common Procedure Coding System (HCPCS) classification code 99281–99285	Dichotomous: • Outpatient-only ED visit = yes/no Count: • Outpatient-only ED visit: average visit number
ED visit with hospital admission	NHATS/Medicare linked inpatient and outpatient claims files	N/A	NCH_CLM_TYPE_CD = 60, 61	Dichotomous: • ED visit with hospital admission = yes/no

Hospice use	NHATS/Medicare linked hospice file	N/A	NCH_CLM_TYPE_CD = 50	Count: • ED visit with hospital admission: average visit number Dichotomous: • Any hospice use = yes/no Continuous: • Hospice length of stay (if any hospice use = yes), mean number of days Dichotomous: • Fee for service: yes/no
Fee-for-service coverage	NHATS/Medicare Beneficiary Summary linked file	N/A	BENE_MDCR_ENTLMT_BUYIN_IND_01 - BENE_MDCR_ENTLMT_BUYIN_IND_12 BENE_HMO_IND_01 - BENE_HMO_IND_12	

NHATS = National Health and Aging Trends Study; LML = last month of life interview; SP = sample person.

Supplementary Table 2

Top 10 Primary Diagnoses for Determining Frequency of Any ED Visit and Associated ICD-9 Codes

Description	ICD-9 Codes
Septicemia	038.0, 038.10, 038.11, 038.12, 038.19, 038.40, 038.42, 038.43, 038.9
Cardiac arrest	427.5
Pneumonia and other respiratory diseases	466.0, 481, 482.0, 482.1, 482.42, 482.83, 482.9, 486
Malignancy	146.0, 150.5, 153.0, 153.1, 153.3, 153.8, 153.9, 154.0, 155.0, 157.1, 157.9, 158.9, 162.3, 162.5, 162.8, 162.9, 163.9, 183.0, 183.8, 185, 191.9, 1921, 193, 197.6, 197.7, 198.3, 198.5, 202.83, 203.00, 225.2, 239.6, 259.2
Congestive heart failure	402.91, 404.91, 428.0, 428.21, 428.23, 428.31, 428.33, 428.40, 428.43
Cerebrovascular disease	430, 431, 432.1, 432.9, 434.01, 434.91, 435.8, 435.9, 438.22, 438.89
Cystitis and other urological infections	590.10, 599.0
Hip fracture and fractures of other bones	820.02, 820.03, 820.09, 820.21, 820.8, 821.00, 821.01, 733.11, 802.0, 802.8, 805.01, 805.02, 805.2, 805.4, 807.01, 807.03, 807.04, 807.06, 808.2, 808.8, 812.41, 822.0
Stomach/intestinal disorders	536.8, 552.20, 552.29, 557.0, 558.9, 560.1, 560.2, 560.89, 560.9, 564.00, 567.22, 569.83, 569.85, 787.91
Fluid and electrolyte disturbances	253.6, 276.0, 276.50, 276.51, 276.69, 276.7

ICD = International Classification of Disease.